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living is published by the British Columbia Persons With AIDS Society. This publication may report on experimental and alternative therapies, but the Society does not recommend any particular therapy. Opinions expressed are those of the individual authors and not necessarily those of the Society.



The British Columbia Persons With AIDS Society seeks to empower persons living with HIV disease and AIDS through mutual support and collective action. The Society has almost 4500 HIV+ members.

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think ⊕

opinion & editorial . . .

Cast your vote at our AGM

by Paul Lewand

For 20 years, the BCPWA Society's mission—self-empowerment for people living with HIV and AIDS through mutual support and collective action—has informed all of our activities, from the strategic planning phase to service delivery, and every program area: support, treatment information, advocacy, prevention, communications, and development.

Society members and associate members alike recognize and respect BCPWA Society's unique organizational structure. As a consumer-driven agency, every individual's voice is valued and considered, but voting and decision-making privileges are reserved for members.

On a day-to-day operational basis, staff, board members, and volunteers participate on numerous BCPWA Society standing committees and subcommittees. Our committee structure provides a dynamic and collaborative arena to report on work carried out, identify priorities for new work, and address emerging issues and challenges.

In standing committees and subcommittees, voting remains reserved for BCPWA Society members. This accountability structure is extended to the next level, where board representatives serving on committees and subcommittees provide regular status reports at bi-weekly board meetings. Our structure ensures that the Society remains an organization created by and for PWAs, and that priorities and directions reflect those of our membership.

BCPWA Society's Annual General Meeting (AGM) is an important yearly gathering of the organization's member-

ship and supporters. Typically, this event involves the presentation of the annual report and financial statements, elections of the Board of Directors for the forthcoming year, and sometimes resolutions and amendments to the bylaws. The AGM is an opportunity to learn more about the Society, ask questions, contribute opinions, meet past and present board members as well as other Society members, and cast your vote for the incoming Board of Directors.

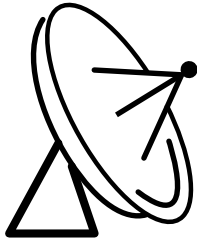
There are 11 seats available on the Board of Directors; to provide more stability and consistency in governance, this year the Society is switching from one-year terms for directors to staggered two-year terms. So if you're a BCPWA Society member, there's all the more reason to attend the AGM and ensure your vote is heard.

This year's Annual General Meeting takes place on Saturday, August 26. See the advertisement on page 16 for more details. We promise a fantastic lunch! If you're unable to attend, we hope you'll assign your proxy to someone you trust.

BCPWA Society is *your* organization. And the directors you elect are committed to the Society's mission—a mission that 20 years later still reflects our passion, our determination, and our dedication. I look forward to seeing you at our AGM. ⊕



Paul Lewand is the chair of the BCPWA Society.



REALITYBITES

News from home & around the world



Show leadership in AIDS fight: church leaders to PM

Twenty church leaders representing the Canadian Council of Churches have written a letter to Prime Minister Stephen Harper, urging him to show leadership in the fight against HIV/AIDS on both the international and national level.

The letter is one of several advocacy efforts by the Canadian Council of Churches leading up to the 16th International AIDS Conference in Toronto. The council, the largest ecumenical body in Canada, will host a pre-conference gathering for faith groups from August 10 to 12.

The council partnered with other AIDS organizations, including the Interagency Coalition on AIDS and Development and the Canadian HIV/AIDS Legal Network, to determine what areas to best lobby the government.

Source: The Catholic Register

Harper "not committed" to drug site

Proponents of Canada's first supervised-injection site for heroin addicts say they don't understand why Prime Minister Stephen Harper isn't committed to the facility that appears to have saved lives and slowed the spread of diseases such as HIV.

Mr. Harper told a news conference on May 25 that the Conservative government is still weighing the fate of the site, where addicts are allowed to shoot heroin or other injection drugs under the supervision of healthcare workers.

The previous Liberal government approved the facility as a three-year pilot project. In September, Health Canada must decide whether to extend its approval.

Perry Kendall, BC's provincial health officer, said there are already enough evaluations in peer-reviewed journals to suggest the site should be maintained. Dr. Kendall is supporting Victoria Mayor Alan Lowe, who wants a supervised-injection site in his city.

Source: Canadian Press

HIV infections "may have peaked"

The rate at which people are infected with HIV may have peaked in the late 1990s, according to a UNAIDS report. It found the incidence of new HIV infections appears to have stabilized for the first time in 25 years. UNAIDS said improved funding and access to drugs appeared to be producing results—but said HIV remained "an exceptional threat."

The agency, which surveyed 126 countries, estimated that 38.6 million people are living with HIV worldwide. It found that approximately 4.1 million people were newly infected with the virus during 2005, and approximately 2.8 million people died of AIDS-related illnesses during the year.

The report warns that young people and children are increasingly affected by the epidemic, and efforts to protect these groups are not keeping pace. It found some countries were doing well on treating people with HIV but poorly on HIV prevention efforts, while in others the opposite was true.

Source: BBC News

French air ticket tax to fight AIDS

French President Jacques Chirac has urged rich nations to follow France's lead

and adopt a one-euro tax on plane tickets to help poor countries buy drugs they need to fight AIDS and other killer diseases. Chirac said the surcharge would help spread the benefits of globalization to people living on less than a euro a day, a level of poverty that prevents those hardest hit by malaria, AIDS, and tuberculosis from receiving treatment.

From July 1, a French law will levy one euro on domestic and European flights and 4 euros on long-haul flights. Business and first class travellers will be charged an extra 10 euros, rising to 40 euros on international flights. The levy is expected to raise 200 million euros (\$238 million) in a full year.

Source: AEGIS-Reuters

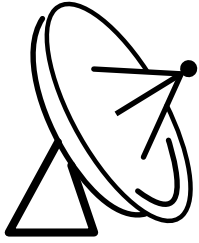
FDA approves shingles vaccine

The US Food and Drug Administration has approved Zostavax, a vaccine from Merck & Co. Inc. for the prevention of herpes zoster (shingles) in individuals 60 years of age and older. While shingles is also common among HIV-positive people, the vaccine is not yet recommended for people with suppressed immune systems, including those with HIV/AIDS.

Shingles is 15 to 25 times more likely to occur in HIV-positive people, regardless of their T-cell counts. In HIV-positive people with significant immune suppression (T-cell counts below 50), there is an increased risk of zoster infection of other parts of the body, including the retina at the back of the eye. This can result in rapid blindness.

While it is possible that the vaccine is safe for HIV-positive people with no or minimal immune suppression, it is recommended that PWAs avoid the vaccine until necessary clinical trials are completed.

Source: AIDSmeds.com



REALITYBITES

News from home & around the world



Online AIDS vaccine database launched

To mark HIV Vaccine Awareness Day on Thursday, May 18, the New York-based AIDS Vaccine Advocacy Coalition launched an online AIDS Vaccine Clearinghouse.

The site is a comprehensive and interactive source of AIDS vaccine information on the Internet, with information on people and organizations involved in vaccine advocacy, research, and global delivery. The Web site and an electronic advocate network are aimed at educating communities on HIV vaccine research and thanking the thousands of volunteers who have participated in clinical trials.

The Clearinghouse includes features that provide easier access for people in developing countries, such as low-tech and text-only features for use with low Internet bandwidth. The coalition will also have key documents available in languages where clinical trials are taking place, as well as portable disks and booklets for those with no Internet or computer access.

Visit www.aidsvaccineclearinghouse.org.

Source: United Press International

Lamivudine monotherapy for resistant virus

For HIV-infected patients receiving highly active antiretroviral therapy (HAART) containing lamivudine and harbouring lamivudine-resistant virus, switching to lamivudine monotherapy may lead to a better immunological and clinical outcome than complete therapy interruption, according to the results of a pilot study.

Dr. Antonella Castagna from Vita-Salute San Raffaele University in Milan and colleagues gave 58 patients with lamivudine resistance either 300mg lamivudine monotherapy once daily or discontinued all antiretroviral drugs for 48 weeks.

They report that CD4 cell-guided treatment interruption in patients with high CD4 counts and detectable viremia led to immunological/clinical failure in more than 70 percent of cases after a median of 20 weeks.

By contrast, continuing lamivudine led to only 41 percent and significantly delayed immunological/clinical failure, with none of the patients experiencing disease progression or grade 3-4 HIV-related adverse events.

Source: Reuters Health

AIDS summit called death by diplomacy

Activists from more than 70 civil society groups from around the world have denounced the United Nations political declaration on HIV/AIDS released June 2nd at the end of a major international gathering.

The UN called the three-day meeting to find out what more needs to be done to fight the HIV/AIDS epidemic. But despite repeated calls from civil society groups, the UN member states agreed on a text that commits no hard targets on funding and treatment.

Its signatories also shied away from admitting that those who are most at risk from HIV/AIDS include drug users, sex workers, and men who have sex with men—communities that certain

governments regard as unlawful and immoral. They are referred to in the declaration as “vulnerable” groups, a term that many consider vague and open to different interpretations.

Many observers hold the US particularly responsible for damaging the prospects of a strong declaration. The US delegation repeatedly moved to weaken the language on HIV prevention, access to low-cost drugs, and targets for treatment funding.

Source: Oneworld.net ☉

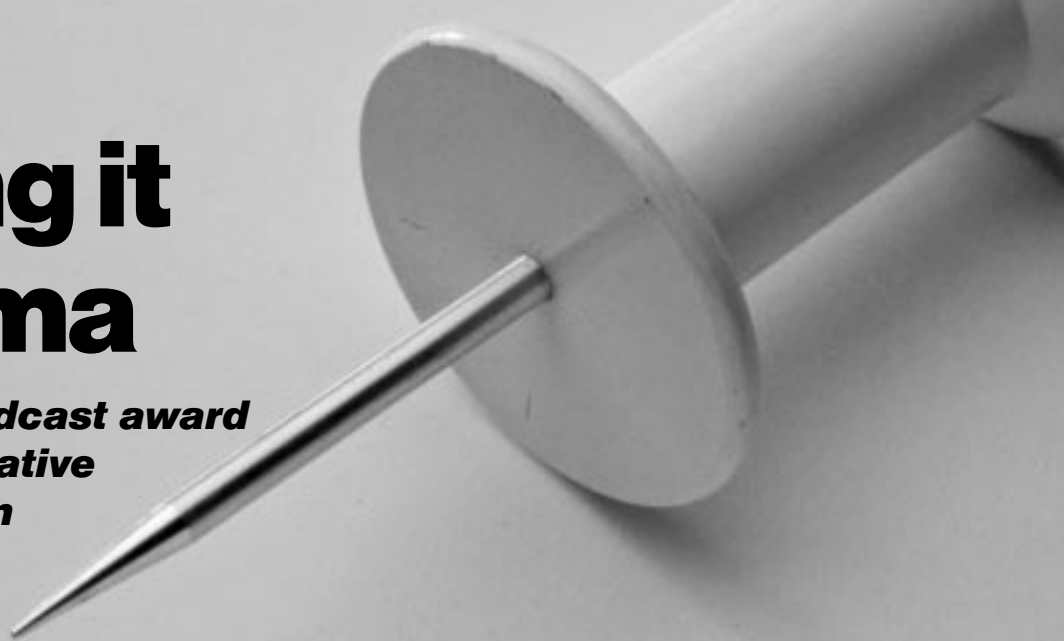


BCPWA Society treasurer Wayne Campbell, BC MLA Jenny Kavan, and Positive Women's Network executive director Marcie Summers attended Giving Women Power Over AIDS, a photo exhibit on microbicides, presented by PWN at Science World, Vancouver on May 31.

Sticking it to stigma

BCPWA wins broadcast award to create a provocative anti-discrimination media blitz

by Glyn Townson



A new campaign to fight stigma and discrimination surrounding HIV/AIDS is being launched throughout BC this summer. Earlier this year, the BCPWA Society was awarded the 2006 Humanity Award from the BC Association of Broadcasters. The award is a broadcast public information campaign; private radio and television stations throughout the province, plus the CBC-TV Pacific Region, run broadcast media advertisements for a full year in every market in BC. Based on current published rates, the campaign has a commercial value of \$3 million.

Over the past 20 years, there has been a huge increase in the number of people living with HIV/AIDS in the province of BC. In 1985, there were 1,362 positive tests in BC (according to BC Centre for Disease Control statistics); by June 2005, the accumulated number had risen to 11,789 (according to Public Health Agency of Canada statistics).

The advertising campaign will challenge people to think about HIV/AIDS in a different way.

People living with HIV face daily stigma and discrimination. Many stereotypes have arisen around HIV, such as the assumption that HIV-positive people are gay or intravenous drug users, both often viewed as disposable groups. Misconceptions and negative stereotyping often affect HIV-positive people's sense of their own worth and their right to participate as full citizens in our society.

To address these issues, Cossette Communications—one of the largest, award-winning advertising agencies in Canada—developed a provocative advertising campaign. The television and radio advertisements will challenge people to think about

HIV/AIDS in a different way. Cossette has generously donated all hard costs associated with producing the television and radio spots, and has also enlisted the support of Steam Films.

In addition to the broadcast advertisements, Fjord Interactive, a division of Cossette, will develop a Web site <www.endHIVstigma.ca>, elaborating on issues of AIDS-related stigma and discrimination, and including links to BCPWA Society's Web site.

A toll free telephone number—1-866-443-AIDS (2437)—will operate throughout the campaign, providing information, support, and referrals to callers.

Brochures and other print materials specific to the campaign will be available by request to persons visiting the Web site or phoning the information line.

Advertising costs for production alone total more than \$50,000, and when you add the commercial value of the ad placements, it's clear that BCPWA Society would not be able to afford this campaign on its own. Therefore, the Society would like to thank and acknowledge all the people who contributed time and resources to the campaign, including: the BC Association of Broadcasters, particularly past-president Brett Manlove and current president Jim Rusnak; the Cossette Communication Group, especially president and creative director Richard Hadden, as well as the creative, production, and account teams that worked on the TV and radio ads as well as the Web site; Steam Films including director Matthew Swanson, and their production crew; the BC Actors' Union and volunteer actors; and the countless community businesses, groups, and individuals who supported BCPWA Society in their application for this award. A special thank you, as well, to the BCPWA Society staff and board members who served on the working group for this project and have made it a reality.

A media and campaign launch was held on June 29th at the Vancouver offices of the Cossette Communication Group. ☉

Glyn Townson is the vice-chair of the BCPWA Society.

Identifying the missing links

ART-LINC Collaboration explores the delivery of antiretroviral treatment in developing countries

by Dr. Paula Braitstein

In the last two issues, Dr. Paula Braitstein has shared her observations from her travels to clinics in resource-constrained settings, as part of her job for the Antiretroviral Treatment in Lower Income Countries (ART-LINC) Collaboration. This article provides an overview of the collaboration itself; it is a summary of a paper that appeared in the International Journal of Epidemiology in October 2005.

Antiretroviral therapy, a combination of at least three potent anti-HIV medications often referred to as highly active antiretroviral therapy (HAART), has prolonged and improved the lives of hundreds of thousands of people worldwide. Its benefits are finally starting to be extended to resource-constrained settings, the situation in which 90 percent of people with HIV/AIDS live.

However, in spite of massive scale-up efforts, as of June 2005, only an estimated 12 percent of people in urgent medical need were receiving treatment in low- and middle-income countries. Still, this percentage represents roughly one million people. Monitoring the effectiveness and safety of antiretroviral medications among these people is crucial: both to ensure the best clinical management of patients and to best inform the continued rollout of treatment.

Identifying what's working and isn't

In 2003, the National Institutes of Health's Office of AIDS Research and the French Agence Nationale de Recherches sur le



SIDA provided funding to set up a research collaboration among HIV-treating clinics in Africa, Latin America, and Asia. The purpose of this operational research collaboration, called the Antiretroviral Therapy in Lower Income Countries Collaboration, or ART-LINC, is to identify what works, what doesn't work, and why, in the delivery and consumption of antiretrovirals. The principal investigators are Professor Francois Dabis of the University of Bordeaux, France, Professor Matthias Egger of the University of Bern, Switzerland, and Professor Mauro Schechter of Universidad do Rio de Janeiro, Brazil.

The specific objectives of the collaboration are to define the effect on survival of people initiating HAART in resource-constrained settings, to compare that effect with survival in high-income settings and to describe program-level factors that influence survival. The main criterion for

participating in the ART-LINC Collaboration was that a clinic be in a low- or middle-income country, treat people with HIV, and electronically collect basic clinical data on their patients. Potential sites were identified by contacting people presenting research at international conferences and through personal contacts of the principal investigators.

A total of 31 centres in 18 lower-income settings were contacted. Twenty-three agreed to participate and 18 sent data, together representing 8,714 people on HAART from Africa (Botswana, Burundi, Cameroon, Democratic Republic of the

Congo, Cote d'Ivoire, Kenya, Malawi, Morocco, Nigeria, Rwanda, Senegal, South Africa, and Uganda), Brazil (two centres), Thailand, and India (one centre each). The database was closed at the end of 2004.

Among these countries, Brazil and India were the first to introduce HAART in 1996, then West and North Africa in 1997 to 1999. HAART wasn't introduced in Thailand until 2000, followed by East and South Africa in 2001. Thirty-nine percent of the centres were government funded clinics and another 40 percent were clinics set up by a non-governmental organization. The remaining sites were private-for-profit clinics. The average number of patients being treated with HAART in a clinic was 542, although it ranged from 70 to 3,000. Most treated children as well as adults.

The cost of treatment varied

In nine centres, the government paid for the treatments, and 16 centres reported having access to generics. How much patients had to pay, if anything, varied: 12 programs charged an average of \$31 US per month and 14 charged for CD4 counts, at an average cost of \$23.50 US. While viral load testing was available in 17 centres, it was expensive: from \$75 to \$100 US. As a result, only 22 percent of patients had both a CD4 and viral load measure at baseline and at six months after initiating HAART. Eleven centres provided completely free treatment and care, or charged a minimal fee by local standards.

The purpose of this operational research collaboration is to identify what works, what doesn't work, and why, in the delivery and consumption of antiretrovirals.

Eligibility criteria and treatment regimens were generally consistent with the guidelines of the World Health Organization. Forty-one percent of all prescriptions were for d4T, 3TC, and nevirapine, but were given as separate drugs—that is, not in a fixed dose regimen—in 22 percent of all prescriptions.

For all the people treated in the ART-LINC Collaboration, only 81 percent had data recorded with their age, gender, and HAART start date recorded, and had at least one follow-up visit. Ninety-two percent of these people had never before received any antiretroviral treatment when they started HAART. Those individuals who had previously received antiretroviral treatment were more likely to be male, to have received treatment before 2002 and to have gone to private clinics.

Only 75 percent of people had a documented baseline CD4

count, with an average of 108 cells/mm³. People with a CD4 measure at baseline were more likely to be women and to be attending public clinics and receiving free care.

Infrastructures not in place

One of the striking findings from this collaboration is that the more recently people started treatment, the less likely they are to have a documented baseline CD4, the less likely they are to have any follow-up, and the more likely they are to be lost to follow-up. These data suggest that clinic infrastructures—including laboratory processing, data entry, and procedures to track patients who miss appointments—may not be able to keep up with the rate at which new patients are starting HAART.

There is much that the ART-LINC Collaboration may be able to contribute. The current phase of the collaboration has 26 clinics and networks participating, including the Mother-to-Child Transmission Plus Network, representing over 35,000 people receiving HAART in 21 countries. Although large, it may not be totally representative. There are few clinics from rural areas participating, and in order to participate in the collaboration, clinics had to be already collecting data electronically, and so the collaboration may over-represent “centres of excellence.”

Approximately 15 percent of patients are lost to follow-up in the first year after initiating HAART; not knowing what happens to people is certainly an issue for clinical research. It is even more important for making the most out of available HIV treatments, and maximizing the effectiveness of HAART in resource-constrained settings. ☉

Key advocacy issues

- 1 The more recently people started treatment, the less likely they are to have a CD4 count documented at baseline.
- 2 The more recently people started treatment, the less likely they are to have any follow-up (in other words, they are being lost to the clinic and the clinic doesn't have the resources in place to track them down).
- 3 Clinics need to be supported and encouraged to maintain complete records on their patients, so that important questions about the effectiveness of HAART can be answered.

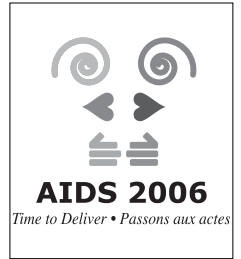
Dr. Paula Braitstein is the epidemiologist and project manager of the ART-LINC Collaboration (Antiretroviral Treatment in Lower Income Countries Collaboration). She is the former BCPWA Society senior policy advisor on health promotion.



BCPWA at AIDS 2006

Our Society will have a strong presence at this year's International AIDS Conference

by Glyn Townson



The final results are in, and BCPWA Society will be well represented at the XVI International AIDS conference in Toronto from August 13 - 18. A total of eight abstracts were selected for either poster or oral presentations.

Poster presentations

- ▶ “The Living Well Lab: establishing a community-based research institute in Vancouver to assess the impact of complementary and alternative medicine on the quality of life and rehabilitation of persons living with HIV/AIDS” – *Carole Lunny, Dr. Francisco Ibañez-Carrasco, J. Evin Jones (Friends For Life)*
- ▶ “Overcoming stigma and discrimination in the health care community-based setting: best practices around educating medical providers in BC through the ABCs of HIV Treatment and Care” – *Carole Lunny, Jane McCall, Kath Webster*
- ▶ “Delivering treatment information services by and for persons living with HIV/AIDS in a community-based setting” – *Zoran Stjepanovic, Gordon Waselnuk, Roy Parish, Michael Connidis*
- ▶ “Web-based action kits, a model of advocacy” – *Suzan K.*

- ▶ “Serosupportive Workshop: the BC Persons With AIDS Society’s groundbreaking workshop to strengthen, affirm, and enhance relationships for HIV serodivergent (HIV-positive and HIV-negative) couples” – *Neil Self*

Cultural Arts Programme poster presentation

- ▶ *living* ☉ magazine covers – *Glyn Townson*

Oral presentations

- ▶ “Inmate report card on harm reduction programs in federal prisons” – *Terry Howard*
- ▶ “People living with HIV/AIDS, a positive force for prevention” (non-abstract) – *Neil Self*

In addition to the high number of BCPWA Society’s submissions that were accepted, to date, 12 members and staff have received whole or partial scholarships to attend the conference.

If you’re planning to attend the AIDS Conference and want to find out when any of these presentations will be taking place, the full conference program and list of plenary speakers can be found on the AIDS 2006 Web site at www.AIDS2006.org. ☉

Glyn Townson is the vice-chair of the BCPWA Society. He has been selected as the official media representative for the Society and will be reporting on items of interest to our membership in upcoming issues.

**BCPWA
Advocacy
gets
results!**



The BCPWA Society’s Advocacy Program continues to work hard to secure funds and benefits for our members. The income secured for February 2006 and March 2006 is:

- **\$56,607** in debt forgiveness.
- **\$136,707.90** in housing, health benefits, dental and long-term disability benefits.
- **\$45,840** monthly nutritional supplement benefits
- **\$2,250.00** in ongoing monthly nutritional supplement benefit for children



Should you stay or should you go?

Some things you'll want to consider before you make the decision to leave the workforce

by Glyn Townson

In previous issues of *living* magazine, we've explored the topic of returning to work, or entering the workforce for the first time, for people living with HIV/AIDS. But there may come a time when you need to consider leaving the workforce, either temporarily or permanently, when managing your

HIV becomes too demanding. This could happen due to medication side effects, HIV-related depression, or when opportunistic infections cause too much stress or too many problems to continue with full-time employment. No matter what the reason, it can be a major quandary.

continued on next page

My own experience of leaving work and going on long-term disability benefits was not without its headaches. When HIV-related health problems first started to occur, I cut my working hours by one-quarter, to allow time for rest and reduce my level of stress. This plan worked for a while. Unfortunately, the major flaw in this approach was that when I was no longer able to work at all, my long-term disability benefit was based on 65 percent of my reduced wage.

Because of the onset of illness, I wasn't able to attend to all the lengthy forms and paperwork. Fortunately, my employer was very accommodating. The first stage was applying for Employment Insurance sickness benefits and then for private long-term disability benefits, which paid 65 percent of wages at the time of the disability, tax-free.

After the first year, the insurance company insisted that I apply for Canadian Pension Plan disability (CPPD) benefits. My first application for CPPD was denied, and after applying for an appeal, the benefits were approved two years after the initial filing. The CPPD benefit was paid out as a lump sum, backdated to the original date of filing. It was a substantial amount of money. The insurance company wanted all the money paid back to them, and the money that CPPD sent was taxable. My tax burden was large that year, as several weeks of vacation time were paid out and there was no additional room for RRSPs.

It was hard to adjust to a much smaller income, but fortunately I had no outstanding debts and my mortgage was paid off. Still, the reality of not returning to work took a huge toll, and on top of the complications and coping with an AIDS diagnosis, depression set in. Limited social opportunities due to medications and illness further complicated matters. I was lucky, though, because I had some good family supports and I attended some support groups. Many PWAs, however, don't have these simple supports.

Battling with the insurer

Most private long-term disability plans don't allow for cost of living increases, and over time your income and buying power decreases. My insurance provider was good for the first few years, but after my employer changed insurance carriers, some problems arose. The first incident occurred when the insurer claimed it had not received a report form and just stopped sending benefits. After some squawking, they issued the back payments.

Still, it was a very stressful experience. It's hard to fight back when you're not feeling well. At the time, I was experiencing severe wasting, major diarrhea, and neuropathy. A couple of years later they sent me for a private assessment with a nurse and one of their doctors. I had kept a very good diary of all my appointments and a log of ongoing problems, so they weren't able to deny my claim. Another couple of years passed and they sent me for vocational assessment, even with my doctor's notes outlining my ongoing problems.

There have been some periods when I have entertained the thought of looking at some form of employment. Unfortunately, after being on so many different forms of salvage therapy over the past ten years, which work for a period of time, problems reoccur. It's difficult to make more than short-term commitments. A great fear about fragile health is that by going back to work, my benefits, however meager, would lapse and if more complications arose, I'd be up a creek without a paddle.

Defining HIV disability

In the past, different markers were used to define HIV and disability, including T4 levels, viral load, and specific opportunistic infections such as peripheral neuropathy, pneumocystis carinii pneumonia (PCP), mycobacterium avium complex (MAC) or Kaposi's sarcoma, plus symptoms of fatigue, wasting, and diarrhea. Today, more than likely the markers will be medication side effects or failure, medication-related stroke and heart conditions; and HIV-related depression, neuropathy, cancer, or severe fatigue.

Currently, we have a lot more information on how HIV affects the human body, and although there is still no cure, there are more treatments and accurate diagnostic tests to assess the progression of disease. But laboratory results show only one part of the story. HIV is a complex disease, affecting us physically, emotionally, and spiritually.

Leaving the workforce, or even cutting back on hours, can be overwhelming, given the importance that work and earnings are valued by our society. Having to leave work can feel like a personal failure, even if it's necessary for survival. The idea of a "disability time-out," however, may be a good short- to medium- term solution if you're experiencing some difficulties.

Questions around a stable income are at the top of the list when contemplating going onto disability. If your workplace doesn't have extended benefits, you'll probably be looking at a combination of public, provincial, and federal benefits. Finding out what benefits you are entitled to and doing some pre-planning beforehand can make your transition easier.

Plan in advance and take some practical measures

Overall financial health is an important consideration when looking at leaving the workforce. Start keeping track of exactly how much you spend each month. It might seem like a lot of effort, but if you keep a diary of all your expenses for a month—even that morning latte—you may find a lot of areas where you could be saving, rather than spending money.

Clearing up credit card debt at high interest rates and paying off car loans and mortgages will allow you to live on less income without loss to your standard of living. While you're still working, maximize your registered retirement savings (RRSP) contributions; even if you have no intention of living to retirement age; this can serve as an income-smoothing tool by allowing withdrawal in periods when

you're unable to work or are waiting for benefits to be processed.

Before you apply for disability benefits, there are a number of things you can do to make the process easier. Keep a detailed diary of symptoms, specific incidents (such as diarrhea, nausea, and fever), laboratory tests, pharmacy appointments, and doctors' appointments, and record the times when your impairments have

Having to leave work can feel like a personal failure, but the idea of a "disability time-out" may be a good short- to medium- term solution if you're experiencing some difficulties.

kept you from normal daily tasks and responsibilities.

Don't gloss over symptoms or exaggerate them; it's important to have accurate accounts of your condition. Sooner or later, someone will be asking questions and it's better to be prepared than to have to rely on memory. After a few years on medications and the effects of aging, memory can be incomplete and could jeopardize your benefits. Make sure your doctors and specialists understand the impact that their statements will have on disability decisions.

Get expert advice and assistance

We all need help when contemplating early retirement or leaving the workplace and going on long term disability. Get feedback from peers, support groups, therapists, physicians, financial advisors, lawyers, and career counsellors. Most of us have had no preparation, training, or experience in moving from work to disability.

When the time comes to apply for government benefits, don't attempt to complete and submit the forms without assistance. Work with agencies that are familiar with the process and the applications.

If you have extended or group benefits at work, get to know your policy. Each one has unique features. You can only hold your insurer to honour the policy if you understand it. Ask your human resources department, or consult someone with a good understanding of the fine print. Make sure you understand how your coverage defines disability, and if you do apply for long-term benefits, does the policy change its criteria after a few years? Does it cover on the basis of returning to your own occupation, or any occupation? What does your background education, training, and previous experience allow you to do?

Talking with an advocate who deals with these situations can also be helpful. Some private insurance companies are

notoriously difficult to work with.

Low or high lab results don't always tell the true story about your ability to work. Keep an accurate daily diary, noting anything that occurs that could get in the way of being able to work. This can serve as a useful treatment tool, spotting patterns of symptoms and issues before they turn into major problems. If a symptom occurs, even once, write it down. There's no room in today's lean and mean environment to miss even small symptoms. Since many jobs require focus, cite any problems in your everyday life with concentration, persistence, pace, memory, or irritability.

Keep a detailed paper trail

List all individual symptoms that occur—but just the facts. Symptoms are what impact your work situation. Help your doctor help you protect your benefits. Give your doctor a copy of the details from your latest diary pages, and ask that they be added to your medical records, or at least noted on in your chart. Ask for a complete copy of your medical records. If symptom and incident reporting are spotty or unclear, ask your doctor to correct the record with a summing-up statement. If you're not getting support from your doctor, get a second opinion.

Some other tips:

- Mark your calendar for anticipated claim review times. Most private insurers review cases yearly.
- Find out who receives the claims form. Check with your doctor to confirm whether or not he/she received a form.
- After a successful review, ask the insurer when you can expect your next review.
- Keep photocopies of all documents and send the originals to the insurer by registered mail.
- If you move, inform your insurer repeatedly of your new address.
- If there's a form to be filled out, make a special appointment just for that.
- Stress the importance of records and official statements to your doctor.
- Treat all income protection measures as a part of your health care.

There are still problems of stigma and discrimination when living with HIV, especially in the workplace. It's not always easy to live openly and honestly with this disease. Working in a hostile environment can be very hard on your health. Remember, you have the final say about what's best for your personal situation. ☺



Glyn Townson is the vice-chair of the BCPWA Society.

FIGHTING WORDS



Show us the money!

The BC government doles out more health dollars but leaves HIV/AIDS in the lurch again

by Ross Harvey

The news ran through BC's HIV/AIDS community like lunch through a PWA on heavy medications.

New money! New money! There's going to be new money!

On November 16, 2005, BC's Minister of Health, the Hon. George Abbott, defended his department's amended budget for the 2005/06 fiscal year on the floor of the provincial Legislature. The Opposition Critic for Health, David Cubberly, posed a series of questions to the minister about funding for the province's community-based HIV/AIDS organizations, in light of the government's dismal failure to achieve the goals set out in its *Priorities for Action in Managing the Epidemic* (see "Where's the beef?", *living* ☉, Issue 41, March/April 2006).

Cubberly pointed out that the funding to HIV/AIDS organizations has remained essentially the same for a decade, and asked "whether the ministry is considering, through health authorities, making a more sustained investment in those kinds of organizations."

Abbott's reply suggested that, yes, more funding was on its way. "HIV/AIDS organizations play an important role in helping us to deal with this challenge," he said, "We have added an additional \$60 million to our budget for

the public health area over the next three years for health authorities to work with AIDS organizations to assist us in trying to meet the very ambitious goals that have been set out."

Not wishing to leave the wrong impression, Abbott was careful to add, "the \$60 million is for public health, not just for AIDS, but AIDS is an important part of it."

The HIV/AIDS community was ecstatic. For the first time in more than a decade, new provincial government money—in sizeable amounts!—was to be injected into their work.

Then a funny thing happened.

Nothing.

As community-based HIV/AIDS organizations across the province started to ask each other about new funding ("Did you get any new funding?" "No, we didn't. Did you get any new funding?"), it became evident that not a single such organization had received an additional penny.

Several dozen organizations confirmed this in Cranbrook at the beginning of March, when they met for the semi-annual Pacific AIDS Network meetings. It was also confirmed that the first installment of the \$60 million had already been distributed to the various health authorities.

So, finally, on March 10, 2006, BCPWA Society chair, Paul Lewand, wrote to Minister Abbott. "We would very much appreciate learning from you the disposition of that initial allocation," he wrote. "More particularly, we would appreciate learning, with regard to each health authority, the amount or amounts allocated and, in each instance, the department, division, office or program to which the allocation was directed within the health authority."

Not wishing to leave the wrong impression, Lewand added, "We seek this information because, to the best of our knowledge, no community-based HIV/AIDS organization has received any of it."

As of this writing, there has been no response from the minister.

And there you have it. AIDS may be "an important part" of the province's public health work but, really, not as important as all that. ☉

Ross Harvey is the executive director of the BCPWA Society.



Strictly for the birds



There's a lot of hype about avian flu, but whether it's a real concern remains to be seen *by Derek Thaczuk*

The word *pandemic* seems to have reached epidemic proportions. Worse than an epidemic—a widespread outbreak of an infectious disease—a pandemic is an infection that has ceased to be contained within a population or geographic region. (For example, the Spanish influenza of 1918–1919, an exceptionally devastating pandemic, spread around the world leaving more than 40 million people dead.)

The scare *du jour* is, of course, avian or bird flu, technically known as H5N1, a strain of influenza virus seen almost entirely in birds. In the eight years H5N1 has been monitored by health officials, it has infected just over 200 humans in scattered locations, all of whom had close contact with infected birds. Slightly more than half of those people have died.

While there have been no confirmed cases of human-to-human transmission, there is concern that the virus could mutate into a form that is easily transmissible between humans. If that happened—and that's a big *if*—the consequences could be truly grim. While infecting relatively few people so far, H5N1 has led to much more aggressive disease than the typical flu, with a sobering 50 percent fatality rate. In April 2006, the Associated Press reported that “the few weapons the United States has to keep it from spreading will do little,” and “a pandemic flu is likely to strike one in three people if nothing is done, according to the results of computer simulation.”

“Just another false alarm”

On the other hand, prominent medical voices have dubbed such doomsday scenarios “just another false alarm.” In a *Globe and Mail* editorial in March 2006, Ontario's former medical officer of health Richard Schabas called the political reaction “a mass hysteria that has lost all touch with its tenuous scientific underpinnings.”

Based on the history of flu outbreaks over the past century, Schabas concludes: “A human influenza pandemic is likely to occur some time in the next 40 years. [But] there is no reliable scientific basis for predicting its timing [or] severity....We should make prudent but limited preparations ...and spend our efforts tackling the myriad of real problems that we actually do face.”

Studies have also recently shown that bird flu may thrive too deep in the lungs to be spewed out by sneezes and coughs, possibly explaining why humans are not easily infected.

But what about HIV-positive individuals? Are they more susceptible? No reason to suppose so, says leading HIV specialist Dr. Joel E. Gallant: “The flu is pretty much the flu [even] if you have HIV,” he says online on Johns Hopkins AIDS Service. In fact, he says, if the flu pandemic of 1918 is any indication, the people with the healthiest immune systems have the greatest mortality probably because they have a more vigorous immune response.

If the flu pandemic of 1918 is any indication, the people with the healthiest immune systems have the greatest mortality probably because they have a more vigorous immune response.

The spectre of a flu mutation

This seeming contradiction could prove to be a larger public health issue. If avian flu infections linger in immunosuppressed people without causing death, it may give the virus time to mutate. The *Wall Street Journal* recently reported, “Because an overreaction of the immune system is what kills bird flu patients, it is precisely immunosuppression among AIDS carriers that could allow them to host the virus longer,” thus possibly triggering the feared flu mutation.

Possibly, if, could, might. What to do in the mean time? No specific recommendations have been issued for HIV-positive or otherwise immunocompromised people and no exposures have been reported in North America. Aside from avoiding infected Eastern-hemisphere poultry, the best thing to do, still, is basically nothing. And to quote Dr. Joel Gallant again, “What will help if we have a global avian flu pandemic, God forbid? Having been vaccinated, taking Tamiflu, and luck.” ☉

Derek Thaczuk is a freelance consultant and medical writer with 11 years involvement in the HIV community.





Be prepared

Will you have enough meds to last you in the event of a pandemic or a natural disaster?

by Glyn Townson

Last year, disastrous storms caused unprecedented flooding in New Orleans. That should be a wake-up call for those of us living in the Lower Mainland. In addition to the devastation and death, thousands of people living near the coastal regions were stranded without access to essential services—including hospitals, clinics, and pharmacies—for weeks. Many HIV-positive patients found themselves without access to medication.

Those of us living on an earthquake belt—the Lower Mainland—or below sea level, as in some parts of Richmond and Delta, are at risk for similar scenarios.

Another issue to consider is the increasing threat from airborne pathogens, like the SARS outbreak in Toronto in 2003 or the current rapid spread of avian flu throughout Asia, parts of Europe, the Middle East, and Africa. The avian flu is expected to arrive in North America within the next year or two. There is also the real possibility of other potent flu strains. Our federal government has taken some initiative to stockpile antivirals such as Tamiflu, but it is unclear how much they are stockpiling and who would qualify for it.

Not enough emergency room capacity

Meanwhile, BC still lacks emergency room beds and equipment for non-pandemic medical needs. Last year at the Royal Columbian Hospital in New Westminister, dozens of people were left in hallways for hours without access to care. More recently, doctors in the Vancouver General Hospital Emergency Department sent an open letter to patients indicating that hospital's emergency rooms were already overstressed and underfunded. The situation is similar throughout the province with many emergency rooms and hospitals either severely cut back or closed entirely.

We must accept that a pandemic or natural disaster will demand individual resourcefulness, in the event that stores are closed and utilities are shut down, or that we don't have access to safe drinking water.

If an earthquake, windstorm, or flooding occurred, would we be able to cope with the consequences if our bridges and tunnels were damaged? Each city and municipality in the Lower Mainland has its own disaster plan, but there hasn't been a lot of coordination between all the players on a master plan, should a major disaster occur.

The federal government has cut back military spending over the past 20 years and closed the Canadian Forces Base in Chilliwack, BC, the closest base to the Lower Mainland. Thus, if a major event occurred, we would likely have to rely on the generosity of our neighbours to the south for assistance.

Have a personal emergency plan in place

While we may not have control over when and how these situations happen, and can't plan for every possible event, it is prudent to prepare a personal plan for emergencies, especially those of us living with HIV/AIDS. Federal government guidelines suggest a minimum of one week's worth of food, drinking water, and first-aid supplies for all households that can afford it. This can be a difficult prospect for those living below the poverty line.

If you're on a fixed income, a simple plan of action is to slowly work on building a small stockpile of essentials. You can store filtered water in used plastic milk jugs that have been washed out and bleached. A few extra tins of soup (ready to eat rather than condensed) and other non-perishable items can add up to a prepared home. Remember to rotate items kept for emergency use to ensure your supplies are fresh and aren't past their expiry date.

For airborne pathogens like a flu outbreak or a norovirus (such as the Norwalk virus), containment is important. We can all do our part by taking basic precautions against spreading these agents. Make it a habit to wash your hands frequently with soap and water, and resist touching your face or rubbing your eyes with dirty hands. Attempt to minimize your exposure by staying close to home; if you must leave home during outbreaks, take public transit at lower volume times or walk.

Plan to have two weeks' extra medication squirreled away in case you can't access your doctor, or the IDC pharmacy has staffing or delivery problems. Be sure to rotate your stock of medications, using your oldest medication first. Maintaining an emergency supply of medication can be problematic because medications can expire; some have a shorter shelf life than others.

Depots are stocked up with meds

Since many BCPWA Society members rely on St Paul's Hospital and the BC Centre for Excellence in HIV/AIDS (BCCfE) for HIV medication, we requested information on the hospital and clinic's emergency preparedness plans. Irene Day, the director of operations for BCCfE and Linda Akagi, the pharmacy outreach coordinator for St. Paul's, outlined and explained emergency plans for a variety of scenarios.

St. Paul's Hospital invested extra attention to emergency preparedness leading up to the year 2000 (Y2K). All departments of the hospital prepared plans for disaster situations. The emergency plans are classed as "code orange" and, depending on the situation, they have specific personnel and plans for in-house and off-site situations.

The St. Paul's Hospital Pharmacy Department currently maintains an on-site inventory of about two weeks' worth of the medications they use. There are also inventories of medications at off-site depots such as the Oak Tree Clinic, the Shopper's Drug Mart on Davie Street in Vancouver, and the Downtown Eastside health clinic. Outside the Lower Mainland, there are also depots in Victoria, Nanaimo, and Kelowna.

Plan to have two weeks' extra medication squirreled away in case you can't access your doctor, or the IDC pharmacy has staffing or delivery problems.

If something should happen to the physical structure at St. Paul's Hospital, the pharmacy could operate out of another site. The Infectious Disease Clinic pharmacy data is backed up each day, and once a week a hard copy is taken off-site to a safety deposit box, that can only be accessed by three designated personnel. Since the present system only backs up once a week, there's the potential to lose up to five days of data. The BCCfE is applying for grant money to create a simultaneous parallel system at a second physical site, which would ensure that data would remain available, even if one of the sites was damaged.

If the hospital or clinics shut down for a period of time, think of what other resources may be available. Find other people you know on similar regimens close to where you live; that way, you can hopefully supplement the shortfalls in each other's medication supplies if you don't have any other access to medication. ☺

Stay informed through these Web sites

* Be prepared and keep yourself informed. Health alerts such as flu outbreaks and updates on avian flu are available on the BC Centre for Disease Control (BCCDC) Web site at www.bccdc.org. You can also check out online resources with basic tips to develop your own emergency plan at the BC Provincial Emergency Program Web site at www.pep.bc.ca and the federal government's Web site at www.safeguard.ca.

Glyn Townson is vice-chair of the BCPWA Society.



Notice of ANNUAL GENERAL MEETING



LOOK FOR YOUR **AGM** PACKAGE IN THE MAIL FROM MID TO LATE JULY 2006.

The membership will meet to receive the Annual Report of the Directors, consider amendments to the by-laws of the Society, if any, elect the Board of Directors of the Society for 2006/2007, and conduct other such business as is deemed necessary in accordance with the constitution and by-laws of the Society.

Members wishing to have business placed on the agenda for the Annual General Meeting should submit it prior to June 19, 2006.

A letter to the Secretary of the Society containing:

(1) a brief paragraph describing the specific intent of the business,
and

(2) a properly worded motion pertaining to the business should
be sent to the Society's registered office at:

1107 Seymour Street, Vancouver, BC V6B 5S8

IMPORTANT DATES TO REMEMBER



Resolutions from the Members to be submitted to the Secretary of BCPWA	by June 19, 2006
Mail out of AGM Packages	not later than July 31, 2006
For individuals who do not receive mail, AGM Packages will be ready for pick up from Member Services (Reception) Desk	on August 8, 2006
Last day Proxies are mailed	August 11, 2006
Last Day Proxies may be requested for Pick up	August 18, 2006

If you have any questions or would like to receive a copy of the Society's Annual Report, please call Derek Bell, Secretary, at 604.646.5317 and leave a confidential message. To ensure accuracy, please spell your last name slowly and leave a contact phone number.



Interpretation for the deaf will be available



treatment. information


TREATMENT INFORMATION PROGRAM MANDATE & DISCLAIMER

In accordance with our mandate to provide support activities and facilities for members for the purpose of self-help and self-care, the BCPWA Society operates a Treatment Information Program to make available to members up-to-date research and information on treatments, therapies, tests, clinical trials, and medical models associated with AIDS and HIV-related conditions. The intent of this project is to make available to members information they can access as they choose to become knowledgeable partners with their physicians and medical care team in making decisions to promote their health.

The Treatment Information Program endeavours to provide all research and information to members without judgment or prejudice. The program does not recommend, advocate, or endorse the use of any particular treatment or therapy provided as information. The Board, staff, and volunteers of the BCPWA Society do not accept the risk of, or the responsibility for, damages, costs, or consequences of any kind which may arise or result from the use of information disseminated through this program. Persons using the information provided do so by their own decisions and hold the Society's Board, staff, and volunteers harmless. Accepting information from this program is deemed to be accepting the terms of this disclaimer.

New BC Centre for Excellence HIV treatment guidelines

by Rob Gair

Just over a year ago, in the January/February issue of *living* , we discussed new HIV treatment guidelines from the International AIDS Society. Recently, the BC Centre for Excellence in HIV/AIDS at St. Paul's Hospital published comprehensive guidelines for the management of HIV infection. The purpose is to provide primary care physicians with the most up-to-date recommendations about HIV therapy in an easy to access, web-based format. The following is a brief summary of these guidelines.

When to start antiretroviral therapy

The decision about when to start therapy in people who have not previously taken HIV drugs is based on symptoms and CD4 count. The viral load is not a factor at this stage. Anyone who has an AIDS-defining illness should be started on highly active antiretroviral therapy (HAART) as soon as possible, regardless of CD4 count. AIDS-defining illnesses are usually bacterial, viral, or fungal infections that occur because of a poorly functioning immune system. They include things like oral thrush, chronic cold

sores or shingles, genital/anal/cervical warts, Kaposi's sarcoma, and tuberculosis. Healthy people who have a CD4 count of 200 or less should also be started on antiretrovirals because they are at high risk of developing an AIDS-defining illness in the short term.

There's a grey area when it comes to healthy HIV-positive people with CD4 counts between 200 and 350. For the most part, these individuals are not offered therapy. However, recent data suggest that individuals in this category who have low CD4 cell fractions are at risk for developing infections. This fraction is calculated by dividing the CD4 count by the total number of lymphocytes in the blood, then multiplying by 100 to express it as a percentage. It is considered a more stable marker for immune function compared to regular CD4 cell counts, which may fluctuate inconsistently. The new guidelines suggest that people with CD4 cell fractions of 15 percent or less should be offered therapy.

The goal of therapy is to maintain an undetectable viral load in the presence of a stable CD4 count.

continued on next page

HIV-positive individuals with CD4 counts above 350 are not offered HAART regardless of other laboratory values, including viral load.

Deciding on which medications to take

There are currently about 20 available antiretroviral medications, which are divided into four classes: nucleoside reverse transcriptase inhibitors (NRTIs, or nukes), non-nucleoside reverse transcriptase inhibitors (NNRTIs, or non-nukes), protease inhibitors (PIs), and fusion inhibitors. Generally, all patients who have not received HAART before are given three different medications: usually two NRTIs as backbone therapy plus either an NNRTI or a PI.

In terms of actual medications, this generally means 3TC (Epivir) plus AZT (Retrovir) or tenofovir (Viread). A new NRTI called FTC (Emtriva) may be used instead of 3TC and abacavir (Ziagen) may be used in place of tenofovir. Older NRTIs like ddI (Videx) and D4T (Zerit) are no longer commonly used as starting therapy.

To round out the HAART regimen, folks are generally given non-nukes like nevirapine (Viramune) or efavirenz (Sustiva) as long as they show no resistance to these medications or have no other reasons for avoiding them. PIs may also be used as the “third agent” instead of an NNRTI. Lopinavir/ritonavir (Kaletra) and atazanavir (Reyataz) are currently the preferred PIs, noting that low-dose ritonavir is always added to these medications to boost their effectiveness. Newer PIs like tipranavir (Aptivus) and darunavir (TMC 114) are reserved for

treatment-experienced individuals with resistance to the first-line PIs.

T20 or enfuvirtide is exclusively reserved for people with multi-drug resistant HIV.

People who have taken HAART previously must have individualized drug regimens. Considerations include current immune status, resistance patterns, side effects or intolerance to medications in the past, and choosing the most convenient drug schedule.

The powerful action of HIV medications in the body means a high rate of side effects. Many people experience upset stomachs, and protease inhibitors are commonly associated with diarrhea. Other common side effects include headaches and rashes. Some adverse effects or problems are exclusive to certain medications or patient populations but not everyone experiences side effects to the same degree. Some of the better-known problems are listed in Table 1.

More detailed information on the BC Centre for Excellence in HIV/AIDS's treatment guidelines is available at www.cfenet.ubc.ca. Click on “Therapeutic Guidelines.” ☉

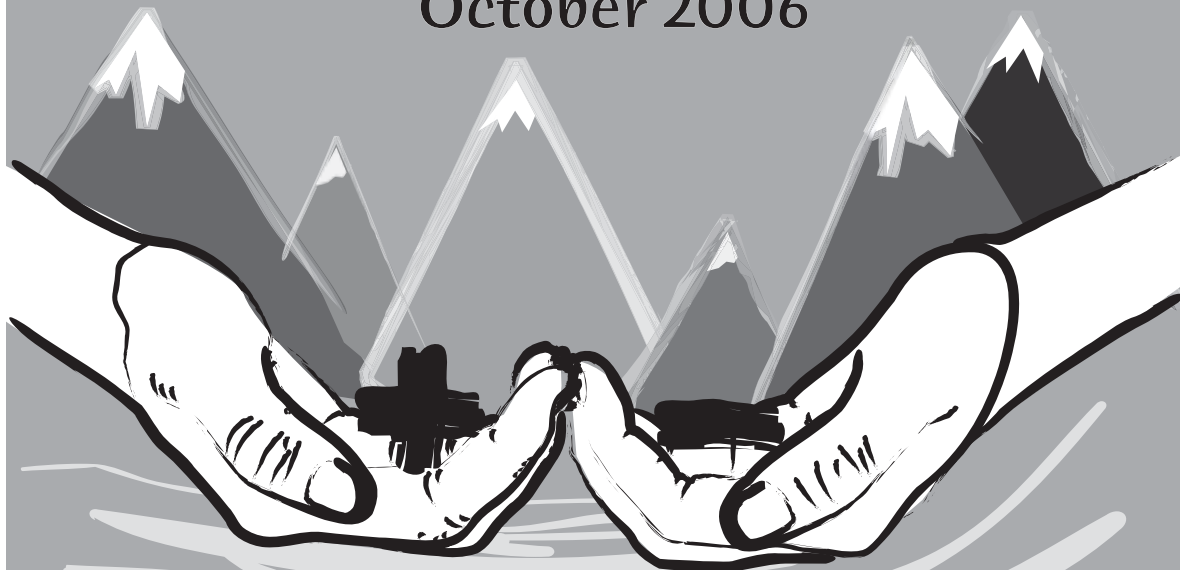


Rob Gair is a BCPWA representative on the Therapeutic Guidelines Committee at the BC Centre for Excellence in HIV/AIDS.

3TC	Well tolerated	
Tenofovir (Viread)	Low phosphate levels, kidney failure (rare)	Increase dairy in diet (for phosphates), monitor kidney function monthly
Abacavir (Ziagen)	10% of people have a serious allergic reaction	Observe closely for first six weeks; stop drug if it occurs
Nevirapine (Viramune)	Serious skin rashes, liver toxicity in first six weeks; higher risk of liver problems in women with CD4 over 250	Monitor liver function in early therapy; avoid in people with hepatitis; avoid in women with CD4 over 250
Efavirenz (Sustiva)	Rashes, bad dreams, euphoria, psychosis; causes birth defects	Avoid in people with mental health problems or women of childbearing age
Protease inhibitors	Diarrhea, rash, elevated lipids	Monitor lipids, may need to take lipid-lowering drugs
Atazanavir (Reyataz)	Acid-lowering drugs reduce effectiveness	Avoid use of acid-lowering agents

Retreat program for HIV+ / HIV- couples

October 2006



SeroSupportive

3 nights / 4 days at a mountain lodge with lake view

- > guided workshops*
- > outdoor activities*
- > socialize*

*strengthen,
affirm,
enhance
relationships*

Information
Session
July 28, 2006

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Making the grade

Are the PWA eligibility criteria for organ transplants fair? BC investigators explore the scientific and ethical issues

by Dr. Timothy Christie and Dr. Julio Montaner



Since the introduction of highly active antiretroviral therapy (HAART) in 1996, rates of morbidity and mortality have fallen significantly among people infected with HIV. People are no longer dying from AIDS-related opportunistic infections. As a result, end-stage liver disease is now emerging as one of the leading causes of death among HIV-positive people, which means that for many of them, a liver transplant is the only treatment option.

Prior to the introduction of HAART, an HIV diagnosis was a contraindication to liver transplantation. Typically, in the pre-HAART era, HIV-positive organ recipients died of infection soon after transplantation and the survival rates for this population were lower than those of the HIV-negative population. In addition, there were concerns about using immunosuppressive medications as this could precipitate opportunistic infections, accelerate progression to AIDS, and decrease survival.

Internationally, outcomes have been reported for approximately 51 HIV-positive individuals who have received liver transplants since 1996. The consensus is that HIV-positive liver transplant recipients currently have comparable one-year, two-year, and three-year survival rates to HIV-negative transplant recipients. Furthermore, post-transplantation survival rates in HIV-positive recipients co-infected with the hepatitis C virus (HCV) appear to be comparable to that of HIV-negative transplant recipients infected with HCV.

According to the Canadian Association of Transplantation, there are nine centres in Canada that perform liver transplants. Although not available in the published literature, we have received anecdotal reports that one Canadian centre performed a liver transplant on an HIV-positive patient three years ago—but this patient has since died. Since then, two Canadians underwent liver transplantation outside of Canada, one of

whom is doing well. There are no published details about these patients, and it is unclear from these other centres in Canada whether they have guidelines for transplanting HIV-positive patients.

BC Transplant Society guidelines as the standard

Because of the paucity of literature on this subject, we have chosen to analyze the BC Transplant Society (BCTS) guidelines because they are the most clearly articulated treatment guidelines in the country. We expect that other provinces will look to the BCTS for leadership on this issue.

The fact that the BCTS guidelines do not exclude patients solely because of an HIV-diagnosis is highly appropriate, as there appears to be no reason for excluding them from the benefits of transplantation.

The BCTS guidelines are as follows:

- ① HIV-positive patients must fulfill all required criteria for liver transplant candidacy that non-HIV infected individuals must fulfill.
- ② HIV-positive patients must have an absolute CD4 count of 200 or more; however, in certain circumstances, provisions could be made to accommodate a lower CD4 count.
- ③ HIV-positive patients must be on HAART while they are on the waiting list (no minimum duration, HAART medications may be changed by HIV specialist at any time—in other words, there is no specific duration “stable dose” required).
- ④ HIV-positive patients must have an undetectable HIV viral load at the time of transplantation.

The fact that the BCTS guidelines do not exclude patients solely because of an HIV-diagnosis is highly appropriate, as there appears to be no reason for excluding them from the benefits of transplantation. In addition, despite the restriction of a CD4 count of 200 or more, the allowance to accommodate patients with lower CD4 cell counts on a case-by-case basis is also welcome for the same reason. However, conditions 3 and 4 of the guidelines, which require that the patient be on pre-transplantation HAART and have an undetectable viral load, have the consequence of precluding many HIV-positive patients from being placed on the transplant waiting list and hence from receiving a liver transplant.

The problem is that many patients are unable to continue HAART because of liver toxicity and patients are often asked to consider liver transplantation in this setting so that they can resume HAART. Furthermore, patients who cannot tolerate HAART prior to receiving a liver-transplant may not be able to achieve the undetectable viral load requirement under condition 4. Similarly, such patients will most likely have a low CD4 count, further jeopardizing their eligibility under condition 2.

The BCTS guidelines correctly offer liver transplantation in HIV-positive patients as a form of treatment. However, they have incorrectly assumed that since most of the people who participated in the studies, which form the basis for these guidelines, were on pre-transplantation HAART, that pre-transplantation HAART is part of the standard of care for this patient population. They further assume that since long-term outcomes are unknown in pre-transplantation HAART intolerant patients—because the issue has not been adequately investigated—these patients should not be eligible for transplantation. It is these specific assumptions that we wish to challenge.

Analysis of BCTS assumptions

We contend that simply because most research protocols specify pre- and post-transplantation HAART requirements, it does not logically follow that pre-transplantation HAART is a necessary condition for a successful transplantation outcome. In fact, it is more likely that these protocols have pre- and post-transplantation HAART requirements, so that somewhat homogeneous populations can be enrolled and compared.

Most of the published studies were conducted as a “proof of principle”—that solid organ transplantation could be performed safely and effectively in HIV-positive patients in the HAART era. The hypothesis tested was not whether pre-transplantation HAART was a necessary condition for successful transplantation, but whether post-transplantation HAART could help improve transplantation outcomes in HIV-positive patients. The objectives were to show the contribution of post-transplantation HAART to improved outcomes in this setting.

The inclusion criteria of two separate experimental protocols clearly illustrate this issue. In fact, nearly identical language is used in these two distinct protocols, one at the University of California in San Francisco and the other at McGill University in Montreal, therefore only the McGill protocol is quoted here. The protocol requires that the research subject be on stable HAART for a minimum of 24 weeks prior to transplantation, with the following caveat:

“Exceptions to this criterion may be allowed at the discretion of the local team (e.g., an excellent transplant candidate in whom antiretroviral drugs cannot currently be tolerated because of liver disease) only if the HIV clinician on the team is confident that they can predict HIV suppression post-transplantation. This assessment should be made based on a thorough review of the patient’s antiretroviral history, HIV-1

RNA levels while on medications, adherence and any resistance tests that are available. If there is any significant doubt about the ability to suppress viral replication post-transplant, the patient should not be enrolled under this criterion.”

What that means is that post-transplantation HAART is far more important than the ability to tolerate HAART pre-transplantation. This consideration was also implemented in the Roland and Stock 2003 study (Review of Solid Organ Transplantation in HIV-Infected Patients, *Transplantation* 2003; 75: 425-429). In this study, all transplant recipients were on pre-transplantation HAART; however, the eligibility criteria specifically allowed subjects who were pre-transplantation HAART intolerant, as long as they were expected to tolerate HAART post-transplantation.

Likewise, a recent paper reporting the Spanish experience (Moreno S. et al., Liver Transplantation in HIV-Infected Recipients, *Liver Transplantation* 2005; 11(1): 76-81) emphasized that the probability of complete viral suppression and immune reconstitution post-transplantation was more important than meeting the CD4 count and viral load eligibility criteria.

Post-transplantation HAART is far more important than the ability to tolerate HAART pre-transplantation.

More specifically, a small study by researchers at the University of Pittsburgh (Ragni M.V. et al. Survival of Human Immunodeficiency Virus-Infected Liver Transplant Recipients, *Journal of Infectious Diseases* 2003; 188: 1412-19) explicitly considered the importance of pre-transplantation HAART and viral load levels in terms of successful transplantation outcomes. They found that survival was significantly poorer among transplant recipients with post-OLT_X antiretroviral intolerance, but not among transplant recipients with pre-OLT_X antiretroviral intolerance. By contrast, a pre-OLT_X CD4 cell count of less than 200 and pre-OLT_X HIV load of more than 400 were not significantly associated with survival.

Therefore, we suggest that the BCTS guidelines may be based on a partial misinterpretation of the available evidence. The fallacy is in the conclusion, that since most of the research subjects in the relevant studies were on pre-transplantation HAART, pre-transplantation HAART is therefore required as part of the standard of care for this patient population. In the relevant studies, it was unanimous that post-transplantation HAART was necessary for a successful transplantation outcome. However, pre-transplantation HAART was not considered a necessary condition for a successful outcome.

Limitations of the analysis

The major limitation of this analysis is our assumption that the motivation for these eligibility criteria is exclusively concerned with achieving good transplantation outcomes. The consequence of this assumption is that other objections to transplanting HIV-positive patients have not been considered in this paper. For example, some critics may be concerned about allocating scarce resources to HIV-positive patients. Or the undetectable viral load requirement may be motivated by healthcare provider considerations rather than transplantation outcomes, such as concerns about the risk to the surgical team in doing complex surgical procedures for patients with HIV.

These types of concerns may be important to discuss but we have assumed that they are not what the pre-transplantation HAART and undetectable viral load requirements are based on. If these eligibility criteria are motivated by something other than successful transplantation outcomes, then those arguments must be made available for scrutiny.

In conclusion, we are simply arguing that if HIV-positive patients satisfy all the criteria for liver transplantation candidacy that non-HIV infected individuals satisfy, the principle of justice requires that these patients be equally eligible for transplantation wait listing. The requirement that HIV-positive patients be successfully treated on HAART to be accepted to the transplantation waiting list is not scientifically justified and thus does not meet the relevant ethical standard.

Ultimately, it is unethical to tolerate unnecessary negative consequences. The consequences of these eligibility criteria are both negative and unnecessary. We therefore propose that the central issue is the probability of a patient tolerating effective HAART post-transplantation and that the requirements for pre-transplantation HAART should be abandoned.

A more detailed version of this article can be found in The Canadian Journal of Infectious Diseases & Medical Microbiology 2006; 17(1): 15-18. ☉

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Julio Montaner, MD, is a professor of medicine
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British Columbia, the director of the BC Centre
for Excellence in HIV/AIDS, and will be the
president-elect of the International AIDS Society
at the conclusion of the
World AIDS Conference in Toronto.



Never giving up

BC's first HIV-positive kidney transplant recipient shares his story

by Sam Friedman

Mike Fulton is British Columbia's first PWA to receive a successful organ transplant and a man with an amazing gift of inspiration and hope to share. He also has an important lesson to offer: that we have the ability to choose to live and love life and to never give up, no matter how difficult our circumstances.

Fulton didn't have any special contacts nor was his transplant a life-saving choice, but the fact that this choice is now available brings us hope, especially for those PWAs who need or will need a transplant to save their lives.

Fulton had insulin-dependent diabetes in 1981 at age 19 and was diagnosed as HIV-positive at 23. For several years, he cared for his dying partner until he passed away. Soon after, at age 38, he went totally blind following a botched operation to fix a diabetes-induced eye problem. "It was like the lights just went out," he says.

But he didn't give up. "My Mom taught me that when life got you down, you had two choices," says Fulton. "You could choose to give up, or you could choose to accept what had happened and move on with a positive attitude; never believing failure was an option. I've always chosen the latter choice."

He got loss/grief support and blindness rehabilitation. Then he enrolled in a virtual university graduate program. But a year later came the flesh eating disease. He stayed optimistic, stuck to his goals, and eventually finished his Masters Degree—but not before the heavy use of antibiotics to stop the necrotizing *faciatis* caused his kidneys to fail. He started dialysis in 1999.

"I couldn't spend the rest of my life relying on a machine to keep me alive, so I immediately began learning everything I could on organ transplants for PWAs," says Fulton. He met with AIDS specialist Dr. Julio Montaner, who reassured him that transplantation was a viable option and that he would advocate on his behalf. Montaner set him up with the transplant team and got him on the transplant list right away. "I still had to be my own advocate, to ensure my transplant was seriously considered, but I never gave up hope that I would succeed!"

After six years of dialysis and advocating for his transplant, making sure the transplant team didn't forget about him, Fulton got the great news: he'd met the new transplant guidelines and a kidney was available. "I knew it would be a tough operation and that organ rejection was a real possibility, but it never deterred me." The transplant operation, in February

2005, was a success. "I was recovering in the hospital when one day I felt this strong foreign urge to urinate—and I did! It was incredible. My new kidney was working!"

"Setting small goals really helps, even if it's just knowing that today I'll get out of the house for an hour to take my dog to the park."

Maintaining his health still dominates his life. He has to take handfuls of antirejection, antiviral, pain, and side-effect management drugs several times a day, and he's monitored monthly. But, he says, having a reason to get out of bed every day helps him maintain a positive outlook. "Setting small goals really helps, even if it's just knowing that today I'll get out of the house for an hour to take Luke, my seeing eye dog, to the park," says Fulton. He's never looked back. "Sure, I get frustrated and angry as hell about everything I've endured, but mostly about not being able to see. It all comes down to our choices and I love my new lease on life."

Fulton feels that maybe he was meant to suffer through all of this adversity so he could help others in their lives. He's happy to talk to anyone, just email him at adventuresindarkness@shaw.ca.

This article is lovingly dedicated to Glen Hillson and all PWAs for whom the new transplant guidelines came too late. ☹

Sam Friedman is a member of several BCPWA Society standing committees, a Canadian Trials Network Community Advisory Committee member, a 2006 International AIDS Conference abstract reviewer, and a dedicated AIDS activist.



That “aha” moment

A new scientific study examines the spiritual transformation that some people undergo in the face of AIDS

by Jari Dvorak

With the recent prayer study by Dr. Herbert Benson of Harvard Medical School (published in the April 2006 issue of the *American Heart Journal*) being a bit of a bust, there is renewed skepticism about the value of scientific research into the link between spirituality and health. Nonetheless, the spirituality-health hypothesis has piqued the interest of many in the scientific community—and research money has begun to flow.

Some even believe that the holy books contain proof that religion and science can be buddies. The Book of Daniel (1:12-15, New King James Version) may well contain the first description of a controlled trial: “Please test your servants for ten days, and let us be given some vegetables to eat and water to drink. Then let our appearance be observed in your presence and the appearance of the youths who are eating the king’s choice food; and deal with your servants according to what you see.’ So he listened to them in this matter and tested them for ten days. At the end of ten days their appearance seemed better and they were fatter than all the youths who had been eating the king’s choice food.”

Of course, since biblical times, biomedical research has advanced significantly. Even the Dalai Lama was reported to be the subject of sophisticated scientific studies involving the latest neuroimaging technologies. More exciting is that much of the current spiritual research is also focused on people living with life-threatening illnesses.

One recent development was the Spiritual Transformation Public Symposium at the University of California in Berkeley. Part of the Spiritual Transformation Scientific Research Program at the Metanexus Institute on Religion and Science, the three-day event in April this year was “the first overall public presentation of the results of 22 rigorous investigations into the nature of the biological, psychosocial, and cultural conditions and factors that underlie spiritual transformations of individuals and groups.” The studies used the latest methodologies and study designs. Roughly 200 attendees from a broad range of natural and social sciences, as well as from various faith traditions and philosophical perspectives, participated in the symposium.

An impressive research team

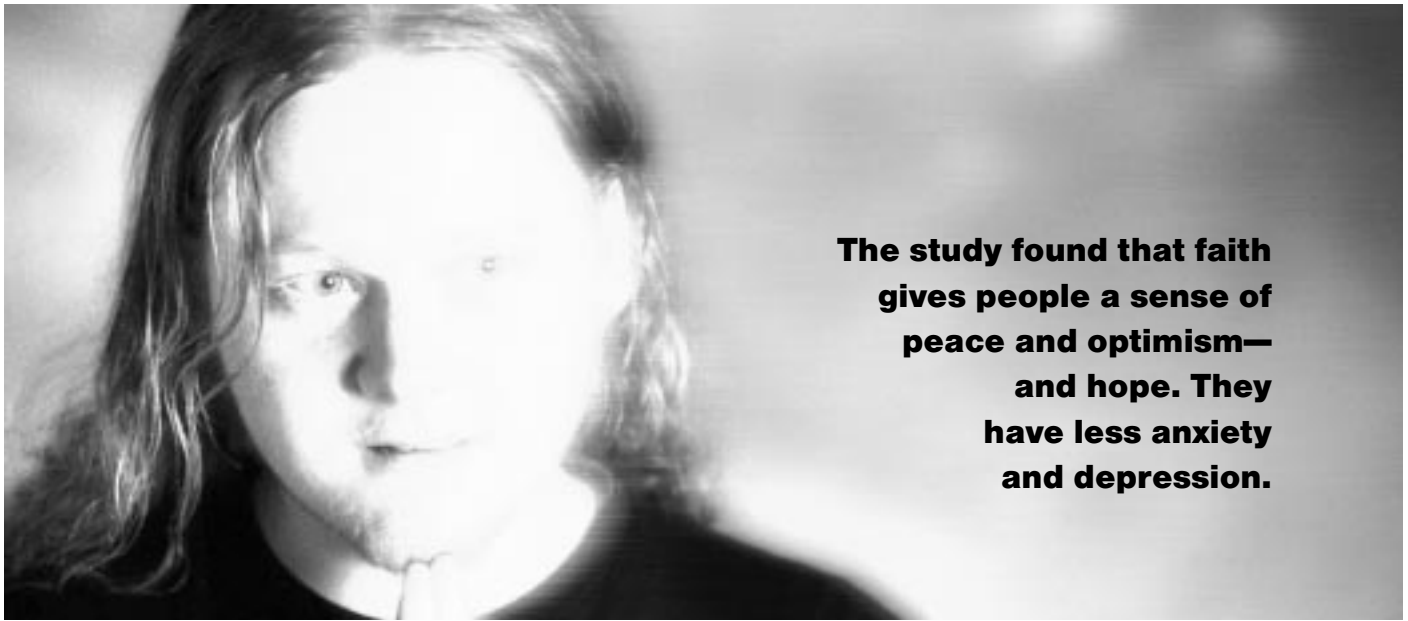
The presentation that created the greatest buzz was the report on the results of a study on spiritual transformation in the face of AIDS. The study is receiving much attention not only because of the interesting results, but also because of the undisputed credibility of principal investigator Dr. Gail Ironson and her distinguished research team, involving, among others, Indiana State University, and the Gallup Poll. Ironson, a professor of Psychology and Psychiatry at the University of Miami, has been involved in numerous studies on the spirituality-health link among HIV and cancer patients.

According to Ironson, one of the most profound crises that people encounter is a life-threatening illness. The reason for probing spiritual transformations in people with HIV is that having such a life-threatening diagnosis causes many people to re-examine their spirituality and relationship with the sacred. Ironson and her team investigated the spiritual beliefs and practices of 79 long-term AIDS survivors, all on antiretroviral medications, who experienced an AIDS-related infection or cancer.

The two main components of the study were questionnaires and in-depth interviews among people who reported having a spiritual transformation, and a longitudinal sample over four years to investigate any spiritual beliefs and practices that could protect the health (in terms of CD4 count and viral load), longevity, and well-being of people with HIV.

About 30 percent of participants had experienced a spiritual transformation. The transformations were most commonly triggered by a spiritual experience after a near-death experience, getting the HIV diagnosis, hitting rock bottom, and/or stopping drugs or alcohol. Participants reported changes in their beliefs, behaviours, values, priorities, and their self-perception. This spiritual transformation gave people a sense of greater meaning and purpose in their life, a more positive view of the sacred and divine, and greater adherence to their HIV medications.

Beliefs and behaviours that were associated with slower disease progression included feeling connection with the greater power, feeling that God loved them, seeing the illness



The study found that faith gives people a sense of peace and optimism—and hope. They have less anxiety and depression.

as an opportunity for growth, as well as prayer, contemplation, and meditation. Conversely, beliefs associated with faster deterioration with HIV included believing God would judge them harshly, turning away from religion and spirituality after the diagnosis, and viewing oneself as a victim.

Long survival and less distress

The research demonstrated strong positive effects—that is, better prognosis and slower progression of the illness—associated with positive spiritual transformation experiences that shape an individual's view of the illness, including seeing it as an occasion for finding meaning and purpose. The study reported strong negative effects on the course of the illness—faster health deterioration—correlated with having negative or punishing views of the sacred/spirit/god. Moreover, the effect of the spiritual variables seems to significantly outweigh the effect of psychological variables such as optimism or depression.

Ironson notes that faith gives people a sense of peace and optimism—and hope. They have less anxiety and depression. And people who are more spiritual are more inclined to help others.

Ironson found that people didn't have to attend formal religious services to get a health benefit, although being a part of a group is beneficial. The research also suggested a few other ways that religious and spiritual coping methods might help mental and physical health, such as offering a sense of control, relieving fear and uncertainty associated with death, and facilitating forgiveness of self and others. Investigators measured participants' levels of the stress hormone cortisol and found that having a sense of peace was strongly related to lower cortisol levels.

Spirituality can be a source of pain, too

The results also note that religion and spirituality may represent a source of pain and struggle for some people with

HIV. Given the links between the religious stigma attached to HIV and its potential to challenge the individual's most deep-seated assumptions about the world, PWAs may experience spiritual struggles. "Before I found out I was HIV-positive, I believed in God, I believed in saints," said one woman in the study. "When I found out I was HIV-positive, I lost hope, I lost faith, and I lost my spirit. I was a bad person. A gray person. I thought I was never going to get out of that stage."

Whether it's a benefit or a burden, the spiritual dimension of HIV may carry significant implications for treatment. The mechanisms through which spirituality affects the mental and physical health of individuals with HIV are not well understood. And, more importantly, spiritually integrated programs for treating HIV have not been developed and evaluated.

What form might a spiritually integrated intervention take for those facing HIV? Right now, the field is wide open for each of us to embark on our own search for spiritual transformation. Perhaps it's time to look into what our spiritual friends have found most helpful. Lately, some of the bigger religions in Canada—Christianity, Judaism, and Buddhism—have been going through a positive transformation of their own, and deserve a second look. Another good starting point might be the mindfulness stress reduction programs offered at major Canadian hospitals. ☉

Jari Dvorak is an AIDS activist, spiritual seeker, and a passionate promoter of meditation. He lives in Toronto with his schnauzer, Dasa.



Training the trainers

Pilot project aims to increase the capacity of rehab professionals to help PWAs

by Glyn Townson



In developed countries, HIV is increasingly defined and viewed as a chronic illness, with episodic periods of wellness and unwellness. People may therefore live with impairments and activity limitations due to their HIV and/or treatment. While various types of therapeutic services can improve the quality of life of PWAs, the challenge is to remove barriers to accessing the services of such rehabilitation professionals as occupational therapists, physiotherapists, speech-language pathologists, and audiologists.

At present, very few rehabilitation specialists actually serve people living with HIV. Results of the Canadian Providers Survey, published in May 2006, reveal that these professionals had seen only a small number of HIV-positive clients and the majority of those were for issues unrelated to their HIV status. In addition, HIV specialists currently provide limited rehabilitation services to PWAs. The study results suggest there is a need for increased information for, and education related to, rehabilitation professionals and HIV specialists.

Part of the solution is to create HIV curricula for rehabilitation professionals that is geared to their respective fields. The Canadian Working Group on HIV and Rehabilitation (CWGHR) has developed a compendium of resources on topics including

rehabilitation-related impairments, activity limitations and participation restrictions, potential intervention strategies, and issues related to sensitive practice, such as ethnicity, gender, HIV stigma, and multiple vulnerabilities. The reference materials also recognize the importance of including people living with HIV as educators, to provide usable information in practical forms such as advocacy sheets and distance learning.

A pilot workshop for rehab specialists

CWGHR also established community and academic partnerships for a pilot course that took place in June in Halifax and Toronto. Two additional courses are planned for Vancouver and Montreal in September.

After these four courses have been delivered and evaluated for strengths and weaknesses, the workshop will be revised to reflect participant and educator feedback. The workshop can then be widely disseminated in a variety of formats.

Several exciting possibilities could develop as a result of this project, such as the development of web-based distance learning, incorporation into study curricula for rehabilitation professionals in universities across Canada, and the adaptation of materials for other healthcare providers.

You need to investigate and question healthcare professionals when you experience restrictions and limitations due to your HIV status. Primary care doctors and nurses often act as gatekeepers who refer HIV-positive patients to rehabilitation services. Yet most of the time, PWAs assume symptoms and side effects are just part of living with HIV, and they don't request referrals for rehabilitation specialists who could potentially help them deal with symptoms or improve their day-to-day functioning. It's also time to advocate for increasing the availability of these services. In most areas of BC, rehabilitation services are severely limited due to funding restraints and healthcare spending cutbacks.

Rehab services to consider

Here are some rehabilitation specialists and the services they can provide:

Physiotherapists are university-educated experts who assist people to achieve their highest level of physical functioning with a personalized treatment plan based on their specific needs. They take into consideration such factors as environment and lifestyle. Physiotherapists can assess your movement, strength, endurance, and other physical abilities; and assess the impact of your injury or disability on physical functioning and physical preparation for work and sports. They can also plan programming and education to restore movement and reduce pain, and provide individualized treatment of your injury or disability.

Occupational therapists are also university-trained health professionals. They work with people to identify difficult activities and help to improve functioning. That can entail: learning alternate ways of doing things, like dressing with one arm, or developing new ways to remember if your memory is poor; helping you maintain or improve strength and confidence; adapting materials and equipment, such as a bath

seat or modifying a toilet seat. Occupational therapists will suggest other changes to your home or work environment. They can also help you develop new skills and abilities for work and leisure through job readiness programs, community programs, or social/recreational activities.

Speech language pathologists may work alone or as part of a team to help people to communicate effectively and to eat and swallow safely. Their role is to identify, assess, treat, educate, and help prevent language, speech, voice, fluency, cognitive, and other related communication disorders and swallowing problems.

Physiatrists are physicians specializing in physical medicine and rehabilitation. They treat a wide range of problems, from sore shoulders to spinal cord injuries. They see patients of all ages and treat problems that touch upon all the major systems of the body. Physiatrists focus on restoring function. They treat acute, chronic pain and musculoskeletal disorders, including those that result in severe functional limitations. They also coordinate long-term rehabilitation processes for patients with spinal cord injuries, cancer, stroke, other neurological disorders, brain injuries, amputations, and multiple sclerosis.

Vocational counsellors assist employees in the transition process of starting in, or returning to, the work force

Mental health and social care workers include social workers, counsellors, and psychologists. These professionals play key roles in helping people deal with conditions such as depression, fatigue, isolation, memory loss, and other factors that limit active living. ☺

For more information on CWGHR and the full report on the HIV and Rehabilitation: Canadian Providers Study, visit www.backtolife.ca

Glyn Townson is the vice-chair of the BCPWA Society.

We need people like you. BCPWA has volunteer opportunities in the following areas:

Website maintenance > Communications

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Special events > AccolAIDS Awards Banquet and AIDS Walk

Writers > *living* ☺ magazine, Communications and Positive Prevention

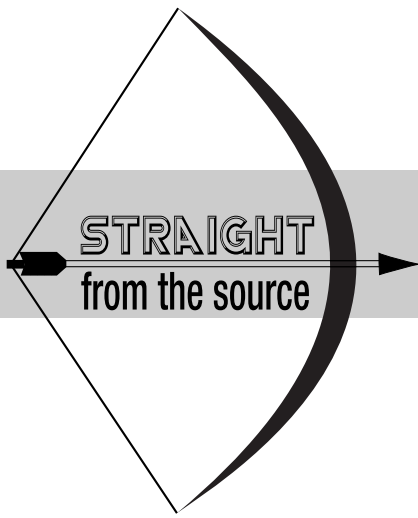
Workshop development and delivery > Positive Prevention, Communications and *living* ☺ magazine

Benefits of becoming a volunteer:

- ◆ *Make a difference in the Society and someone's life*
- ◆ *Gain work experience and upgrade job skills*
- ◆ *Find out more about HIV disease*

If you are interested in becoming a volunteer and/or to obtain a volunteer application form, please email volunteer@bcpwa.org, call 604.893.2298 or visit www.bcpwa.org.

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what's new in research

Assisted injection: A tale of two high-risk groups

by Anne Drummond

Many injection drug users (IDUs) need help when injecting illegal drugs. This need appears to be most common among women IDUs, younger IDUs, and individuals who have little experience with injection techniques or those who are anxious about the procedure. In addition, IDUs favouring jugular injection due to loss of accessible veins will also solicit assistance with injection. Injection into the jugular carries risks for vein damage or cerebral complications, plus the “hit doctors” who are assisting will often use the same equipment they used to inject themselves.

A recent study by Jacqueline O’Connell and Thomas Kerr, researchers at the BC Centre for Excellence in HIV/AIDS Research (BCCfE) at St Paul’s Hospital in Vancouver, showed that people who required help with injecting had an HIV incidence almost double that of those who didn’t need help with injecting. While a number of studies have shown that there are elevated health risks for the person requiring assistance, less is known about the health risks of the people who provide assistance.

Nadia Fairbairn and colleagues at the BCCfE recently published a study that explored the characteristics associated with providing assistance with injection of illicit drugs.

Between March and December 2004, they collected behavioural and drug use data from 704 participants who had previously been recruited into the Vancouver Injection Drug User Study (VIDUS) cohort. This data revealed that 27 percent of participants had provided help with injecting during the six months prior to their interview. Individuals who provided assistance reported engaging in high-risk behaviours, including syringe lending, frequent heroin or cocaine injection, and binge drug use. These assistants most frequently helped close friends or casual friends, and about half the people who provided assistance did so in exchange for drugs and, to a lesser extent, for money.

Thus, not only do these “hit doctors” carry a huge risk of transmitting infectious diseases such as HIV and HCV to those they assist by syringe lending, they also represent an extremely

high-risk group with increased potential for drug-related harm as a result of their own risky behaviour.

This study is important because not only does it identify two groups at very high-risk for infectious disease transmission and other drug-related harm, it also informs the debate around prohibition of assisted drug injection in safer injection facilities (SIF). Although SIFs have been shown to reduce risks such as syringe sharing, the rules prohibiting assisted injection have been associated with a reduction in willingness to use SIFs, especially among women and youth—the two groups at highest risk for HIV infection. As a consequence, IDUs requiring assistance with injecting are forced to do so under circumstances and in environments that expose them to numerous health risks.

Individuals who provided assistance reported engaging in high-risk behaviours, including syringe lending, frequent heroin or cocaine injection, and binge drug use.

The high risks involved in assisted injecting and the profile of both the assistant and the assisted indicate the need for some directed intervention to reduce the harm inherent in these practices. In the absence of any change to current regulations regarding assisted injecting in SIFs, at the very least individuals involved in assisted injecting could be informed about the dangers and how these could be offset by proper sterile injecting techniques. ⊕

Anne Drummond is a medical writer with the BC Centre for Excellence in HIV/AIDS at St. Paul’s Hospital in Vancouver.

LTB4 study is a natural

by Julie Schneiderman

More than 30 years after Canadian scientist Dr. Pierre Borgeat discovered it in a Stockholm lab, Leukotriene B4 (LTB4)—a naturally occurring substance that activates the body's leukocytes or infection-fighting white blood cells—is making its mark on HIV.

Through a Canadian HIV Trials Network pilot study (CTN 213), researchers are hoping to gain some new insights into fighting the virus. The study is set to assess the safety and anti-retroviral activity of LTB4 when used in HIV-positive people. Researchers will be looking for reductions in HIV viral load, as well as measuring the effects on CD4, CD8, and neutrophil (a type of white blood cell) counts, as well as chemokine production.

Dr. Richard Lalonde, CTN's Quebec regional director, together with co-investigators at seven sites across the country, are eager to see whether the documented cascade of biochemical reactions triggered by LTB4 will lead to a chain of activity that naturally blocks CCR5 receptors—the co-receptor for HIV. Without anywhere to land, the HIV virus would be hindered or potentially prevented from further replicating. Lalonde explains that for those newly infected with the disease, this could mean a prolonged period of time before antiretroviral therapy is initiated.

Dr. Julio Montaner, CTN National co-director and director of the BC Centre for Excellence in HIV/AIDS, is heading the LTB4 study site in Vancouver at St. Paul's Hospital. He acknowledges that through ways that are still not fully understood by science, HIV prevents the immune system from working properly. As a result, people infected with HIV/AIDS

appear to produce lesser amounts of LTB4 and have much lower CD4 counts. "The exciting part of this study is that it might give us a window into how we can use the body's own substances to help boost the immune system and fight HIV," he says.

The enthusiasm for LTB4 expressed by Lalonde and Montaner stems from promising findings in earlier studies in test tubes and mice. In order to determine whether LTB4 will have the same effect on viral load in humans, 40 participants will undergo four weeks of active treatment by intravenous injection plus two weeks of safety follow-up. The randomized, double-blind study will include two LTB4 groups and one placebo arm.

Dr. Lalonde is grateful to the CTN, and in particular the Community Advisory Committee, which he feels is contributing to the success of the study by providing a community perspective and helping to facilitate recruitment.

CTN 213 is expected to complete enrolment in the late spring. Early data should be available by mid- to late summer. Given this tight timeframe, we will not have to wait long to see whether LTB4 is a natural therapy for HIV—a Swedish and Canadian dose of common sense. ☺

Julie Schneiderman

is the communications manager at the Canadian HIV Trials Network in Vancouver.



Trials enrolling in BC

- CTN 147** — Early Versus Delayed Pneumococcal Vaccination
BC sites: Downtown Infectious Disease Clinic (DIDC) and St. Paul's Hospital, Vancouver; Medical Arts Health Research Group, Kelowna General Hospital
- CTN 167** — OPTIMA: Options with Antiretrovirals
BC sites: DIDC, St. Paul's Hospital, and Viron Health, Vancouver; Cool Aid Community Health Centre, Victoria; and Medical Arts Health Research Group, Kelowna General Hospital

- CTN 189** — 3TC or No 3TC for HIV with 3TC Resistance
BC sites: DIDC and St. Paul's Hospital, Vancouver; Cool Aid Community Health Centre, Victoria
- CTN 213** — Dose finding and proof of concept study of Leukotriene B4 (LTB4) as ART
BC site: St. Paul's Hospital, Vancouver

To find out more about these and other trials, check out the **Canadian HIV Trials database** at www.hivnet.ubc.ca/ctn.html or call Sophie at the CTN 1.800.661.4664.

Breaking the habit

Methadone maintenance therapy has a number of benefits for co-infected injection drug users

by Libby Hattersley

It is widely recognized that injection drug use impairs a person's ability to adhere to an antiretroviral regimen, which in turn affects treatment outcomes and increases the potential for developing multi-drug resistant strains of HIV. In addition, hepatitis C (HCV) co-infection occurs frequently among HIV-positive injection drug users (IDUs), increasing the risk of severe liver damage and raising a number of treatment issues.

Methadone maintenance therapy (MMT) is currently the most widely prescribed therapy for opiate drug dependent IDUs and studies show that it improves antiretroviral therapy adherence and treatment outcomes among HIV/HCV co-infected individuals. There are some potential drug interaction and adherence issues, but if these are well understood and managed, people can achieve optimal therapy for HIV infection, HCV, and drug dependency.

Reducing opiate cravings

Methadone, a synthetic narcotic analgesic (pain reliever), was first developed as an alternative to morphine for use in pain management. While it's still used for this purpose, methadone has become better known for its use in drug therapy programs for heroin and other opiate dependencies. Administered correctly, methadone can significantly reduce cravings for opiate drugs such as heroin. This is because methadone, itself an opioid, produces many of the same effects in the brain as heroin, but without the euphoria and with a slower onset of withdrawal symptoms. In addition, since it is almost always administered as an oral solution, MMT reduces needle use and therefore the risk of HIV and HCV transmission.

The goal of MMT is to eliminate drug abuse in a controlled way so that IDUs can work on getting their health, personal relationships, home life, and financial and legal situations in order before attempting detoxification. Thus, a comprehensive methadone maintenance program combines methadone administration with monitoring, counselling, support, and

rehabilitation services. MMT is a long-term treatment program, and people will remain on it until they demonstrate that they are fully ready for gradual detoxification.

MMT has the potential to improve antiretroviral adherence—the mechanism by which HIV RNA suppression, CD4 cell count response, and other treatment outcomes are achieved—by reducing drug use and providing opportunities to address other potential barriers to adherence, such as a chaotic lifestyle and poor physical and mental health.

Some recent studies

A recent Vancouver study looked at antiretroviral therapy adherence and treatment outcomes among 278 HIV-infected IDUs enrolled in the Vancouver Injection Drug Use Study (VIDUS). Almost all of the participants were co-infected with HCV. Researchers found that MMT was independently associated with a reduction in heroin use, as well as improved highly active antiretroviral therapy (HAART) adherence, HIV RNA suppression, and CD4 cell count response. The investigators concluded that MMT likely reduced drug use enough to allow for adequate HAART adherence, which translated into improved treatment outcomes.

Researchers also pointed out that engaging in a system of care that requires close follow-up, along with the numerous general health and social benefits that can arise from MMT (including increased employment, enhanced physical and mental health, and improved social functioning), is likely to have a favourable impact on the course of HIV and tolerability of HAART.

A number of recent studies have shown favourable results for integrating MMT and HAART within a combined, directly administered treatment program. In one study among 54 HIV/HCV co-infected IDUs who were participating in a methadone treatment program in Vancouver's Downtown Eastside, 65 percent of participants had achieved viral suppression two years after the study began. More than half of the patients

required methadone dose adjustments to achieve ongoing suppression of opiate withdrawal symptoms, thus highlighting the need to closely monitor drug interactions.

Formally combining MMT and HAART in a directly observed treatment program appears to be an effective way to improve adherence—and therefore treatment outcomes. While few of these integrated programs currently exist, and those that do are still in the early stages of development and evaluation, they offer promise for the future.

Drug interactions can happen

Methadone is metabolized by the cytochrome P450 system in the liver. Drug interactions involving this system are common, and since many antiretrovirals affect this system by either inducing or inhibiting the cytochrome P450 3A4 enzyme, there’s the potential for interactions between methadone and certain antiretrovirals.

Drug interactions may initiate methadone withdrawal symptoms (thus increasing the risk of relapse), reduce a person’s ability to adhere to his/her antiretroviral regimen (through an increase in undesirable side effects), or reduce the effectiveness of an antiretroviral therapy regimen. Therefore, people undergoing concurrent MMT and antiretrovirals must talk to their healthcare provider if they’re concerned about a potential drug interaction or suspect they’re experiencing methadone withdrawal symptoms.

The current evidence available on potential interactions between antiretrovirals and methadone is summarized in Table 1. While individuals should be aware of the potential for these interactions, drug-drug interactions are hard to predict, and whether they occur or not can differ significantly from individual to individual. Therefore, people need to discuss dose adjustments, of either methadone or an antiretroviral medication, with their primary care physician.

In addition, hepatitis C co-infection can exacerbate the effects of methadone-antiretroviral interactions due to impaired liver functioning brought on by the hepatitis C virus (HCV) itself, and by the effects of certain antiretroviral medications. Therefore, HIV/HCV co-infected individuals on MMT require close monitoring and potentially frequent dose adjustments to improve therapy adherence and reduce the potential of relapse.

In BC, primary care physicians prescribe MMT, with methadone dispensed by community pharmacies. There are clinics and community health centres that offer MMT services throughout the province; however, due to the intensive, multi-disciplinary, and long-term nature of this type of therapy, not all clinics offering MMT services are able to take on new clients at any given time. ⊕

Libby Hattersley is a research volunteer with the BCPWA Society’s Treatment Information Program.

	Antiretroviral medication	Potential interactions with methadone	Significance



Boning up on vitamin K

This little-discussed vitamin is being recognized for its role in strengthening bone structure

by Diana Johansen

We rarely hear about vitamin K but we should be paying more attention to it because it's emerging as an important factor in bone health. This fat soluble vitamin was originally recognized for its role in blood coagulation because it is needed to generate thrombin, a crucial factor in blood clotting. But more recent studies have focused on its role in bone structure. This makes vitamin K nutrition of particular interest to people living with HIV/AIDS, since they're more likely to develop osteopenia (thin bones) or osteoporosis (very thin bones).

Typically bone health is assessed by a dual-energy x-ray absorptiometry (DEXA) scan, which measures bone mineral density (BMD). The roles of calcium and vitamin D are well understood for their contribution to BMD and we have well-established intake guidelines for these two nutrients. However, the strength of the bone is also influenced by the quality of its structure, as well as bone turnover (the replacement of old bone with healthy new bone). We are now learning more about the need for a strong protein structure to hold the minerals like calcium.

That's where vitamin K comes in. The main role of vitamin K in bone metabolism is to activate, by a process called carboxyla-

tion, three proteins that contribute to the structure of the bone: osteocalcin, matrix Gla protein, and protein S. Inadequate carboxylation of these proteins due to low vitamin K status may lead to a weak bone structure and ultimately increase the risk of fractures. Theoretically, a person could have good BMD and still have a high fracture risk because of a weak bone structure. Scientists are still trying to understand this mechanism.

Theoretically, a person could have good bone mineral density and still have a high fracture risk because of a weak bone structure. Scientists are still trying to understand this mechanism.

Because vitamin K is a fat soluble vitamin, it does require some dietary fat (fat in the foods we eat) to be absorbed into your body. After your body absorbs vitamin K, it's used up fairly quickly so you need to replenish it every day. Two forms of vitamin K are biologically available to the human body: vitamin K-1 (phylloquinone) is the main source of dietary vitamin K, and is found in green vegetables and vegetable oils; vitamin K-2 (menaquinone) is found in animal meats, dairy products, and fermented foods. Menaquinone is also produced by "good" bacteria that live in the bowel. The recommended dietary intake of vitamin K is 120 micrograms for men and 90 micrograms for women. The best sources are broccoli, cabbage, kale, lettuce, Brussels sprouts, and other greens (see "Sources of Vitamin K" table).

US studies report that many people don't get enough vitamin K in their diet, mainly because they don't eat enough green vegetables. Inadequate intake of the vitamin has been linked to subclinical vitamin K deficiency, meaning low blood levels but no symptoms. Individuals with chronic diarrhea and fat malabsorption can also develop a vitamin K deficiency because it must be absorbed with the fat. Although intestinal bacteria contribute only a small portion of the needed vitamin K, chronic use of antibiotics that wipe out the friendly gut bacteria can also lead to decreased vitamin K status. As well, large doses of vitamin E (greater than 1000 IU) or vitamin A may interfere with absorption or metabolism of vitamin K.

Vitamin K can be measured in the blood as phylloquinone, which reflects your most recent dietary intake of vegetable sources of the vitamin. The functional level of vitamin K is measured by looking at the amount of carboxylated osteocalcin.

This is a more indirect measure of the amount of it in the blood but probably a better evaluation of whether there is a sufficient amount of vitamin K to activate the bone proteins adequately—in other words, whether there is enough to do the job versus there being enough circulating in the blood. The actual test measures the percentage of uncarboxylated osteocalcin. These measures are generally used only in research settings, because there is still little understanding of what the results mean and what to do about them.

Still, you should make an effort to get enough of this important vitamin each day. The foods that provide the most vitamin K are also powerhouse sources of other vitamins, minerals, and antioxidants. Vitamin K supplements are not widely recommended because we don't know the right amount for safety and efficacy. Also, you shouldn't take vitamin K supplements with some medications, especially warfarin (Coumadin). While a large amount of vitamin K from food has no known toxicity, a high-dose supplement could be toxic. Multivitamins in Canada do not usually have vitamin K in them. It's possible to buy vitamin K supplements, but talk to your dietitian and doctor first. ☺



Diana Johansen, RD, is the dietitian at Oak Tree Clinic in Vancouver. She specializes in HIV.

Sources of vitamin K	
Amount of vitamin K (micrograms)	Type of foods (1/2 cup serving size)
[Large black trapezoid]	
[Medium black trapezoid]	
trace	meat, milk, cheese, apples, bananas

Ask the dietitian

If you have a diet or nutrition question, email it to dietitian@bcpwa.org or mail it to *living +*, BCPWA Society, 1107 Seymour Street, 2nd Floor, Vancouver, BC V6B 5S8.

Another so-called miracle cure

by *Kristen Yarker-Edgar*

I've heard that mangosteen juice strengthens the immune system. I've also heard that it's antiviral, antibacterial, and antifungal. What do you know about it?

A lot of people are talking about mangosteen juice these days. It's the latest panacea, purported to help fight over 30 ailments, from cancer to migraines to obesity. An Internet search yields innumerable Web sites trumpeting the benefits of mangosteen juice, including antiviral, antibacterial, antifungal, and immune system-boosting properties. Benefits that, they claim, have scientific proof.

Unfortunately, the science behind these health claims is not as strong as you may be led to believe. Research is far from proving that drinking mangosteen juice will prevent or cure any ailment.

What studies have found is that mangosteen is rich in antioxidants. These antioxidants include xanthones. In test tubes (also known as *in vitro* studies), some of these xanthones have been shown to kill certain strains of leukemia cells, liver cancer cells, and tuberculosis cells. In test tubes, some mangosteen xanthones have also blocked serotonin and histamine receptors, leading to mental health and anti-allergy claims.

It's exciting that science has shown that the mangosteen has the potential for healing diseases that modern medicine can't cure. What the educated consumer must understand, however, is that potential doesn't equal cure. Around the world, researchers are investigating thousands, if not millions, of natural substances to find cures for the ailments of humankind. From the many that initially show potential, few prove any effect.

A test tube is not the same as the human body. After *in vitro* studies come animal studies (in *vivo studies*). Most substances don't make it past this stage. After animal studies, potential cures must be proven in clinical trials using human patients.

Scientists are far from proving in human trials that mangosteen juice cures anything. Even traditional use can't support its health claims. People in Southeast Asia, where the mangosteen grows, traditionally used it two ways: as a drink to fight diarrhea, and as a paste to treat skin irritations.

Frankly, I'm surprised to see such strong health claims based on antioxidants. Antioxidants were hyped as humankind's great saviour, but they have fallen short of being miraculous. The most highly touted haven't done much good in clinical trials.

The manufacturer of the most common mangosteen juice, XanGo Juice, is doing well. XanGo Juice can't be purchased in retail stores in Canada; it is sold privately through multi-level marketing, where independent distributors recruit others to sell it. Even the XanGo Juice Web site has a disclaimer that the product "is not intended to diagnose, treat, cure, or prevent any disease."

My opinion is that mangosteen juice is a lot of money to spend on unproven claims. I recommend eating 10 servings of vegetables and fruit each day. While it still hasn't been fully determined why, research strongly supports that people who eat the most vegetables and fruit are the healthiest. If it's because of the antioxidants, vegetables and fruit with intense colours—such as berries and dark leafy greens—have the highest concentrations.

It's hard to know if the beneficial qualities of vegetables and fruit are lost when they are bottled in juice format. However, if you want the ease of a juice, pomegranate juice is high in antioxidants and costs only about \$5.00 for 500mL. ☺

Kristen Yarker-Edgar, MSc, RD, is a dietitian with the ADAPT program at the Vancouver Native Health Society. She is a member of Vancouver Dietitians in AIDS Care.



Pressure cooker

Hypertension can cause all sorts of nasty problems to vital organs

by *Kristin De Girolamo*

Hypertension is known as the silent killer, but what, really, is the big deal about it? Chronically high blood pressure itself isn't the culprit, it's the damage it does to body tissue that's dangerous. Brain, eye, kidney, and heart tissue are most at risk; for example, if the heart pumps consistently high pressure blood, its walls will get thicker. Thick walls make it difficult to pump blood, thus increasing the risk of heart attack. In the brain, eyes, and kidneys, hypertension can lead to excess pressure on blood vessels, which can burst and cause internal bleeding: this, in turn, can lead to a stroke.

Hypertension is defined as a consistently high blood pressure of 140/90 mmHg; normal blood pressure is around 120/80 mmHg. As many as 20 percent of North Americans are believed to be hypertensive, but 90 percent of these cases have no physical illness, such as narrowing of kidney arteries. A diagnosis of hypertension is associated with lifestyle factors (such as stress, obesity, and smoking) and physical factors such as race or menopause.

PWAs need to watch out for drug interactions with HIV medications.

Another important factor in hypertension is the Renin-Angiotensin system (RAS). The angiotensin-converting enzyme (ACE) converts Angiotensin 1, which has a relatively minor effect on the body, to Angiotensin 2, a potent vasoconstrictor which makes blood vessels narrower, thus increasing blood pressure. Blocking either ACE or the site in which Angiotensin 2 binds will inhibit the vasoconstriction action, lowering blood pressure.

Hypertension can be treated without medication by increasing fluid intake and decreasing salt intake, but usually doctors recommend a drug regimen. Diuretics such as hydrochlorothiazide (sold under many brand names) can increase the amount of fluid the body eliminates, which causes an overall decrease

in blood volume, thereby decreasing blood pressure.

As far as medical treatments are concerned, calcium plays an important role in the vasoconstriction process by causing the constriction. Drugs known as calcium channel blockers can be used to block the constriction process, which causes the blood vessels to widen and thus decrease the pressure of the blood flowing through them.

Drugs that work on lowering the heart rate can also work to lower blood pressure by decreasing the force and speed of the heart beat, thus lowering the amount of blood (or oxygen) the heart needs by lowering its workload. These drugs include beta blockers and drugs that decrease the amount of adrenaline released; both work to overall decrease heart rate.

PWAs need to watch out for drug interactions with HIV medications. When calcium channel blockers are taken with amprenavir (Agenerase), lopinavir/ritonavir (Kaletra), and ritonavir (Norvir), the interaction causes a higher dose of the calcium channel blocker to be present due to enzyme competition. Therefore, the starting dose should be lowered and closely monitored throughout the duration of therapy.

Beta blockers such as atenolol (Tenormin) interact with atazanavir (Reyataz) and cause an increase in the presence of atenolol in the blood due to both drugs using the same enzymes to break them down. However, the interaction is minimal and usually doesn't require a dose adjustment.

So far, there is no documented interaction between the other antihypertensives and HIV medications. But similar to starting any new drug regimen, you should closely monitor any interactions and report any unusual side effects to your healthcare provider. ☺



Kristin De Girolamo is a volunteer with the Treatment Information Program at the BCPWA Society.

Are you HIV-positive?
www.bcpwa.org



**British Columbia
Persons With AIDS Society**

living ⊕ Magazine
Fundraising Events
Treatment Information
Support Services
Volunteer Opportunities
Advocacy Services
Positive Prevention
Prison Outreach

604.893.2200

Volunteering at BCPWA

Profile of a volunteer:

Mayu Uchino



" Mayu is one of those volunteers you can leave alone and know everything will be okay. She always has a smile on her face and treats everyone equally; I guess that's why we love her."

Mike Verbugt,
Member services coordinator

Volunteer history

None, other than at BCPWA.

Started at BCPWA

April 2005

Why pick BCPWA?

I wanted to get involved in working in community-based organizations that serve a mutual and direct support.

Why have you stayed?

It's been challenging, insightful, informative, and entertaining. I also enjoy having a feeling of shared moments with *everybody* here.

Rating BCPWA

A 9 out of 10 because volunteering here gives me a deep and high satisfaction. Also there is a sincere respect and tremendous amounts of humour. Every time I encounter amusing moments, I laugh from the bottom of my stomach.

Strongest point

To gain as many experiences as possible and make use of them for your self-growth.

Favourite memory

When I was having a hard time dealing with a member at the front desk, other members helped me out by talking to him, which made my procedure easier. I thought, "oh ya, this is the mutual support that I'm talking about."

Future vision of BCPWA

I believe consistency in service provisions will make BCPWA more dependable.



Interested in writing?

We need articles on HIV-related prevention, advocacy and treatment. Volunteer for *living* ☉ magazine...

Volunteers should possess the following skill sets:

- Ability to analyze and distill information
- Excellent research and writing skills
- Ability to work independently

Here's what one of our writers had to say: "I find the whole process challenging and rewarding, not to mention the 'feel good' feeling after finishing a piece." Volunteering for *living* ☉ provides the flexibility to work from home.

If you are interested in becoming a volunteer writer and/or to obtain a volunteer application form, please email volunteer@bcpwa.org, call 604.893.2298 or visit www.bcpwa.org.

where to find help

If you're looking for help or information on HIV/AIDS, the following list is a starting point.

A Loving Spoonful

Suite 100 – 1300 Richards St,
Vancouver, BC V6B 3G6
604.682.6325
e clients@alovingspoonful.org
www.alovingspoonful.org

AIDS Memorial Vancouver

205 – 636 West Broadway,
Vancouver BC V5Z 1G2
604.216.7031 or 1.866.626.3700
e info@aidsmemorial.ca www.aidsmemorial.ca

AIDS Society of Kamloops

P.O. Box 1064, 437 Lansdowne St,
Kamloops, BC V2C 6H2
t 250.372.7585 or 1.800.661.7541
e ask@telus.net

AIDS Vancouver

1107 Seymour St, Vancouver BC V6B 5S8
t 604.893.2201 e av@aidsvancouver.org
www.aidsvancouver.bc.ca

AIDS Vancouver Island (Victoria)

1601 Blanshard St, Victoria, BC V8W 2E2
t 250.384.2366
e info@avi.org www.vic.aids.org

AIDS Vancouver Island (Nanaimo)

t 250.701.3667

North Island AIDS (Courtenay)

t 250.830.0787

North Island AIDS (Comox)

t 250.902.2238

AIDS Vancouver (Langley)

t 250.753.2437

North Island AIDS (Port Moody)

t 250.338.7400

ANKORS (Nelson)

101 Baker St, Nelson BC V1L 1A1
t 250.505.5500
f 250.505.5500
http://kics.bc.ca/ankors

ANKORS (Cranbrook)

205 – 14th Ave, Cranbrook BC V1C 3W3
250.426.3383 or 1.800.461.1111
f 250.426.3221 e ankors@kics.bc.ca
http://kics.bc.ca/ankors

Asian Society for the Prevention of HIV/AIDS (ASIA)

210 – 119 West Pender St,
Vancouver, BC V6B 1S5
t 604.669.5567 f 604.669.5567
e asia@asia.bc.ca www.asia.org

BC Persons With AIDS Society

1107 Seymour St, Vancouver BC V6B 5S8
604.893.2200 or 1.800.994.2437
e info@bcpwa.org www.bcpwa.org

Dr Peter Centre

1100 Comox St,
Vancouver, BC V6E 1K5
t 604.608.1874 f 604.608.4259
e info@drpeter.org www.drpeter.org

Friends for Life Society

1459 Barclay St, Vancouver, BC V6G 1J6
t 604.682.5992 f 604.682.3592
e info@friendsforlife.ca
www.friendsforlife.ca

Healing Our Spirit

3144 Dollarton Highway,
North Vancouver, BC V7L 1A1
t 604.875.8758
e info@healingourspirit.com
www.healingourspirit.com

Living Positive

1100 West 10th Ave.,
Vancouver BC V6H 1Y1
t 604.682.2437 or 1.800.616.2437
e info@livingpositive.ca
www.livingpositive.ca

McLaren Housing Society

200 – 649 Helmcken St,
Vancouver, BC V6B 5R1
t 604.669.4090 f 604.669.4090
e mclarenhousing@telus.net
www.MCLARENHOUSING.COM

Okanagan Aboriginal AIDS Society

101 – 266 Lawrence Ave.,
Kelowna, BC V1Y 6L3
t 250.868.8161 f 250.868.8161
e info@okanaganabidsociety.com
www.okanaganabidsociety.com

Positive Living North

1100 West 10th Ave.,
Vancouver BC V6H 1Y1
t 604.682.2437 or 1.800.616.2437
e info@livingpositive.ca
www.livingpositive.ca

Pacific AIDS Network c/o AIDS Vancouver Island

1601 Blanchard St.,
Victoria V8W 2J5
t 250.881.5663 f 250.881.5663
e erikages@pan.ca www.pan.ca

Positive Living North

1-1563 2nd Ave,
Prince George, BC V2L 3B8
t 250.562.1172 f 250.562.3317
e info@positivelivingnorth.ca
www.positivelivingnorth.ca

Positive Living North West

Box 4368 Smithers, BC V0J 2N0
3862 F Broadway, Smithers BC
t 250.877.0042 or 1.886.877.0042
e plnw@bulkley.net

Positive Women's Network

614 – 1033 Davie St, Vancouver, BC V6E 1M7
t 604.692.3000 or 1.866.692.3001
e pwn@pwn.bc.ca www.pwn.bc.ca

Purpose Society HIV/AIDS program

40 Begbie Street
New Westminster, BC V3M 3L9
t 604.526.2522 f 604.526.6546

Southwest HIV/AIDS Network Society

1100 West 10th Ave.,
Vancouver BC V6H 1Y1
t 604.682.2437 or 1.800.616.2437
e info@livingpositive.ca
www.livingpositive.ca

Victoria AIDS Resource

441 East 10th Ave.,
Victoria BC V8W 2E2
t 250.388.6620
e vnhs@shaw.ca

Victoria AIDS Resource Service Society

1284 F Gladstone Ave, Victoria BC V8W 2E2
t 250.388.6620 f 250.388.6620
e varcs@islandnet.com
www.varcs.org/varcs./varcs.nsf

Victoria Persons With AIDS Society

#330-1105 Pandora St., Victoria BC V8W 2E2
t 250.382.7927 f 250.382.3232
e support@vpwas.com www.vpwas.com

YouthCO AIDS Society

205 – 1104 Hornby St.,
Vancouver BC V6Z 1V8
t 604.688.1441 f 1.877.968.8777
e information@youthco.org
www.youthco.org

For more comprehensive
listings of HIV/AIDS
organizations and services
please visit www.bcpwa.org.

Upcoming BCPWA Society Board Meetings:

Date	Time	Location	Reports to be presented
July 5, 2006	1:00	Board Room	Written Executive Director Report / Executive Committee Financial Statements — May
July 19, 2006	1:00	Board Room	Standing Committees
August 2, 2006	1:00	Board Room	Quarterly Department Reports / Written Executive Director Report Financial Statements — June / Director of Communications & Education
August 16, 2006	1:00	Board Room	Executive Committee / Director of Support Services
August 30, 2006	1:00	Board Room	Written Executive Director Report / Standing Committees

BCPWA Society is located at 1107 Seymour St., 2nd Floor, Vancouver.

For more information, contact: Alexandra Regier, office manager Direct: 604.893.2292 Email: alexr@bcpwa.org

BCPWA Standing Committees and Subcommittees

If you are a member of the BC Persons With AIDS Society, you can get involved and help make crucial decisions by joining a committee. To become a voting member on a committee, please attend three consecutive meetings. For more information on meeting dates and times, please see the contact information on the right column for the respective committee that you are interested in.

Board & Volunteer Development

Contact: Teresa Stancioff

☎ 604.646.5377 ✉ teresas@bcpwa.org

Community Representation & Engagement

Contact: Ross Harvey

☎ 604.893.2252 ✉ rossh@bcpwa.org

Education & Communications

Contact: Melissa Davis

☎ 604.893.2209 ✉ melissad@bcpwa.org

Positive Gathering

Contact: Stephen Macdonald

☎ 604.893.2290 ✉ stephenm@bcpwa.org

IT Committee

Contact: Ruth Marzetti

☎ 604.646.5328 ✉ ruthm@bcpwa.org

living+ Magazine

Contact: Jeff Rotin

☎ 604.893.2206 ✉ jeffr@bcpwa.org

Prevention

Contact: Ross Harvey

☎ 604.893.2252 ✉ rossh@bcpwa.org

Support Services

Contact: Jackie Haywood

☎ 604.893.2259 ✉ jackieh@bcpwa.org

Treatment Information & Advocacy

Contact: Jane Talbot

☎ 604.893.2284 ✉ janet@bcpwa.org

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living+

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Vancouver BC

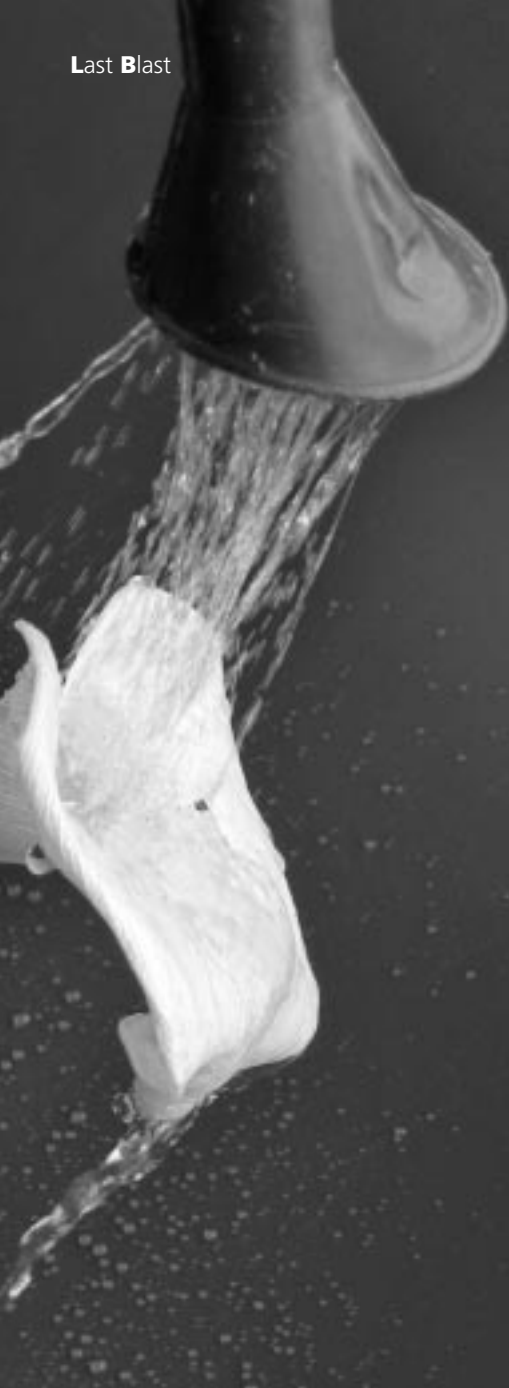
Canada V6B 5S8

For more information visit

www.bcpwa.org

e-mail to living@bcpwa.org

or call 604.893.2206



Royal flush

The fine art of anal douching

by Rob Gair

Anal sex is great. But anal sex with a messy bottom is, well, not so great.

Most of us remember the occasional time when there's been a little too much fudge in the factory—very embarrassing. Sometimes it's unavoidable, but with a little advance preparation there'll be no more dirty diapers for you.

Most gay guys learn about rectal douching from friends or lovers but proper technique is a little tricky and early results are often far from satisfactory. My first lesson came from an unlikely source. During a pharmaceuticals lab a bunch of us fresh-faced pharmacists were getting instructions on how to counsel patients on the use of over-the-counter preparations. When it came to the section on enemas, not surprisingly no one was eager to volunteer a demonstration—not even me! Fortunately, our dowdy-looking female instructor didn't press the issue. Instead she handed out some enema pamphlets and we reviewed the step-by-step directions:

- ① Remove the tip from the nozzle.
- ② Lie on your left side.

At this point, she said, "Why do we tell people to lie on their left side?" We were all stumped and looked at her with blank faces. She smirked and gave us a quick anatomy lesson. Just inside the anus is the anal canal, which merges into the lower part of the rectum. When you're douching, it's good to get these areas clean but if you want to have a really hygienic bum, you need to flush out the lower colon. And the lower colon enters the rectum—you guessed it—from your left side. Lying on your left allows gravity to pull the water into your nether regions where it can do its work.

Armed with my new knowledge about the mechanics of enemas, I got some practical tips from my friend Bunny (so called because he liked hopping on a particular piece of male anatomy). Mostly I wanted to know what equipment to get and where to get it. Bunny suggested I buy a rectal syringe from the drugstore.

Here are seven basic steps:

- ① Purchase a large rectal syringe (a vaginal syringe also works).

- ② Fill your bathroom sink with lukewarm water.
- ③ Squeeze the syringe to expel the air, and quickly immerse it in the water as you let go. Once it's full you're ready for action.
- ④ Lie on your left side and insert the tip of the syringe into your anus (you may want to apply some lube on it to make things easier). Squeeze the contents of the syringe into your rectum.
- ⑤ Stay lying on your left side for a few minutes to allow the water to get to your lower colon.
- ⑥ Sit on the toilet to let the water out. Some water may remain in the colon so take your time to allow it all to come out. Reading material is recommended if you're bored (try *Anal Pleasure and Health* by Jack Morin).
- ⑦ Repeat steps two through six until the "rectal effluent" is clear (yes, we medical people actually use that term). You may need to repeat several times depending on...well, just depending. If you follow these directions you'll be clean as a cucumber. Trust me.

Oh, and one more thing. Some people don't like to use rectal syringes because they don't hold enough water. In that case, you can buy an enema kit that attaches to your shower. The more expensive ones require some plumbing expertise and they're not easily removed when your mother comes to visit. A Web site called www.leatherpost.com sells a cheaper travel bidet: a rubber hose with a so-called "universal" adapter that is supposed to fit onto your bathtub faucet. It didn't fit any of my faucets, but that's another story. If you go for this option, be sure to keep the water pressure low and make sure it's not too hot.

That's it boys (and girls if you're so inclined). Happy douching. And remember—everything comes out smooth in the end. ☺

Rob Gair is a pharmacist and contributing writer for *living* ☺ magazine.